



ALL OF US



FROM HELPING HAND

ALS Canada ambassador Carol Skinner with her mom Louise Sharman



FROM LEADING MINDS



STRONG VOICES TO

Penny Mills at an ALS Canada support group



GENEROUS HEARTS

Team It's Pammer Time!! at the WALK for ALS



MESSAGE FROM ALS CANADA CHAIR AND CEO

WE ARE IN THIS TOGETH

Anyone who has been touched by ALS will tell you it is not an easy journey. For many people, support from family, friends, and the healthcare system plays an important role in managing the increasing complexities of living with ALS.

The same is true for the work of the ALS Society of Canada. We are part of a passionate and compassionate community united by a shared cause: a deep desire to transform ALS from a terminal to treatable disease, while also responding to the challenges people experience living with the disease today. Our community includes not only people and families affected by ALS but also the service providers, donors, and volunteers who make our day-to-day work possible; ALS societies in each province, advocates, and researchers with whom we work on a national stage; and leading academics and scientists internationally who are partners in advancing our collective knowledge about ALS in order to identify pathways for the development of effective treatments.

As you will read throughout this report, the work we have done together means the ALS community is poised for promising change. Many leading researchers believe that effective ALS treatments will be a reality in the relatively near future, thanks in part to the success of the Ice Bucket Challenge, which is already having an impact: in July 2016, researchers announced that the gene *NEK1* has been found to play a significant role in the development of ALS. Our partnership with the Brain Canada Foundation (with financial support from Health Canada), which provided \$10 million in matching funds for ALS research following the

Ice Bucket Challenge, continues to amplify our research investment and was responsible for an additional \$2.7 million in funding beyond our own 2016 research funding.

A significant focus for ALS Canada in 2016 was the important strategic work of readying the organization for the future. For example, we sought feedback from people who receive services and support from our organization to tell us what is working well and what isn't – so we can do a better job of meeting their expectations and needs. We improved our internal systems so we can monitor our financial picture

On the advocacy front, our efforts resulted in the formation of an all-party ALS Caucus on Parliament Hill. With MPs and senators at the table, the ALS Caucus will help to mobilize support to address care and research challenges. An additional research highlight is our participation in Project MinE, an international initiative that will map the DNA profiles of 15,000 people with ALS, establishing a global resource of human data that is expected to identify new genetic causes of the disease and pathways for treatment.

There is still so much to accomplish. But we know that the ALS community is a

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As you will read throughout this report, the work we have done together means the ALS community is poised for promising change.

in a timely way. This will help us to be a more nimble organization and in turn donors can feel confident that we are maximizing our operating efficiencies. Following a rigorous peer-reviewed process, we were accredited by Imagine Canada's Standards Program, the gold standard that recognizes excellence in charitable transparency, accountability and operations. For our stakeholders, this is a reflection of our ongoing commitment to upholding the trust people place in our organization.

resilient one – and that working together, strong and determined, we can together face the challenges and opportunities of the future head on.



Geneviève Bertrand, Chair



Tammy Moore, CEO

ALS CANADA LEADERSHIP

BOARD OF DIRECTORS

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

Geneviève Bertrand, Chair
Dr. Heather Durham
Nick Egarhos
Ronald Foerster
Dr. Angela Genge
Anne Marie Giannetti
Christine Hoyt
Dr. Charles Krieger
Josette Melanson
Patrick Merz
Rick Morgan
Vincent Quinn
Daniel Rivero
Julie Trpkovski

SCIENTIFIC MEDICAL ADVISORY COUNCIL (SMAC)

SMAC provides strategic advice to the Board and management of ALS Canada to ensure all research activities contribute to the vision of ALS Canada, are aligned with the organization's strategic priorities, informed by best practices, and carried out with integrity. SMAC also facilitates collaboration within the Canadian ALS research community and supports its involvement in international initiatives.

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

CLIENT SERVICES ADVISORY COUNCIL (CSAC)

CSAC is composed of individuals with a variety of ALS experiences and expertise who provide input and perspectives to support us in improving the journey of people and families living with ALS in Ontario. CSAC serves in an advisory capacity to the Board, making recommendations for client service program delivery, community partnerships and provincial advocacy.

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

REVENUE ADVISORY COUNCIL (RAC)

RAC acts in an advisory capacity to develop and support new and existing revenue-generating initiatives that will ultimately fund our charitable purpose. Reporting to the Board on ongoing initiatives and potential impact on revenue, its members use and facilitate personal and professional networks to generate interest in fund development initiatives and secure leadership gifts.

Daniel Rivero, Chair
Geneviève Bertrand
Nick Egarhos
Naguib Gouda

TOGETHER, WE CAN

Perspectives

"I remember a family feeling inconsolable when they realized their mom could no longer live at home. When I went to the long-term care facility to meet the staff and help with the transition, it relieved so much stress for them. Sometimes it's a relatively simple solution like installing a hospital bed next to a single one so a husband and wife can stay sleeping side-by-side. Or finding a hospice facility willing to offer the use of a specially equipped bath when bathing at home is no longer an option."

LAURIE LAXER

ALS Canada Regional Manager

"I remember our first home visit with Sarah, the ALS Canada Regional Manager in our area. My top worry was how I was going to manage to give Denis the care he needed once his symptoms worsened. I knew I'd be there full of love and support, but I couldn't imagine how I would be physically able to look after him, and I worried about the enormous financial cost. I didn't mention it to him because I didn't want to add to his troubles, but when Sarah reassured me I would be well supported when the time came, I burst into tears. Just knowing she would be able to anticipate our needs and help us along the way was a huge relief."



TOM DANDO

His spouse, Denis, is
living with ALS

CLIENT SUPPORT AND SERVICES

RECEIVING AN ALS DIAGNOSIS is overwhelming, and living with the disease can be a lonely and frightening time. Whether you are living with ALS or caring for someone with ALS, there are a great deal of challenges and changes to consider. Throughout this journey, what's important to know is that you are not alone.

ALS Canada connects with people living with ALS and their caregivers to serve as a guide on their journey. Whether helping to navigate the complexities of the health-care system, identify community supports, find answers to questions, or provide access to equipment that responds to mobility and communication limitations, we are here to help.

Improving support for people living with ALS today

Survey respondents told us they value the work of ALS Canada's Regional Managers – the members of our staff team who are in the community, meeting with people and families in their homes to help them navigate their journey. Survey respondents also told us they would benefit from more frequent interaction with their Regional Manager. This is not surprising given that there are eight Regional Managers throughout Ontario, and they collectively serve more than 850 clients at any one time.

We also received feedback about our equipment program, which helps people living with ALS to cope with the daily challenges of decreasing mobility and

FIND STRENGTH

In 2016, we continued to support the needs of people and families living with ALS, helping where possible to fill the gaps in care and support not addressed through the healthcare system. But we also went one step further. We asked the people and families we serve to tell us about their experience with our services. We fielded a survey to better understand what is working well from the perspective of our clients, and what needs to be improved. This feedback is essential in order for us to be able to provide the level and type of service people expect.

communication ability through access to equipment and assistive devices.

As a result of the feedback that clients and caregivers shared with us through the surveys, changes to client services and support are being made in 2017 including the addition of more Regional Manager positions located closer to the communities where our clients live to respond to the strong desire for more frequent touchpoints. Together, these efforts will enable us to provide clients and caregivers with more of the support and strength they need through their journey with ALS.

WHO RECEIVED SUPPORT FROM ALS CANADA IN 2016?

At any one time, more than 850 Ontarians living with ALS are benefiting from ALS Canada's support and services.

More than 1,100 people received services from ALS Canada, including more than 250 people who registered with us in 2016.

ALS Canada Regional Managers conducted more than 1,000 one-on-one visits with people and families living with ALS.

More than 600 people accessed our equipment program and many more continued to use equipment provided in prior years.

Our clients collectively requested more than 3,500 pieces of equipment – a 34% increase over 2015.

Support groups took place in 15 Ontario communities, with 175 separate support group meetings taking place over the year.

ALS Canada Regional Managers delivered nearly 100 educational sessions to healthcare providers and community groups.

An ALS research lab
at the Montreal
Neurological Institute

TOGETHER, WE CAN

Perspectives



DR. CHRISTEN SHOESMITH

Director, Motor Neuron Disease Clinic,
London Health Sciences Centre;
Member, Client Services Advisory
Committee, ALS Canada;
Co-investigator for two ALS Canada
clinical research fellowship grants

"With the explosion of new ALS research in the last 10 years, and the many new avenues of investigation opening up, I believe there is good evidence to suggest we are close to discovering effective treatments. I have personally trained two recent recipients of ALS Canada clinical research grants, and feel heartened by the importance placed by ALS Canada on funding ALS research at leading research centres across the country."

"ALS Canada is a trusted organization that has rigour in identifying and supporting initiatives with scientific merit. I became ALS Canada's Ambassador for Project MinE as a way to express my gratitude and give back. I am calling on Canada to get on board with it and really do something to drive a good cause that has the potential to change many people's lives worldwide."

CHRIS MCCAULEY

Social worker, policy research analyst,
ALS patient and ALS Canada
Ambassador for Project MinE

RESEARCH

WHAT CAUSES ALS? How can progress of the disease be slowed? Which areas of focus are most likely to result in effective treatments the fastest? These are the burning questions everyone with ALS deserves an answer to. And together, we are getting closer to answers.

Investments in research have always been a reason to be hopeful that one day there will be effective treatments for ALS. As a result of generous donor contributions and partnerships with provincial ALS Societies, ALS Canada invested \$3.5 million in research grants in 2016, with the Brain Canada Foundation providing \$2.7 million in matching funds. A further \$840,000 was invested in additional research initiatives.

Transforming ALS into a treatable, not terminal disease

As just one example of a recent development in ALS research, July 2016 saw researchers announcing that the gene NEK1 has been found to play a significant role in the development of ALS. This discovery is the result of an 11-country research collaboration that included three Canadians, one of whom was directly funded by the ALS Canada Research Program.

Also in 2016, ALS Canada identified the Canadian research team that will be collaborating as part of an international effort to identify the genetic patterns that lead to the development of ALS and ways in which to better target treatments for the disease. The international project, called Project MinE, will map the full DNA profiles of 15,000

2016 RESEARCH INVESTMENTS

Approximately \$6.2 million was invested in ALS research grants and awards: \$3.5 million from ALS Canada, \$2.7 million of which was matched as a result of our partnership with the Brain Canada Foundation, funded 20 projects across the country.

More than 150 researchers across the country attended the ALS Canada Research Forum, an opportunity to share knowledge and identify opportunities to collaborate.

More than 200 Canadians logged on to the first-ever virtual research forum, a day-long initiative featuring speakers from the Canadian and international research communities.

ALS Canada supported 15 Canadian researchers in attending the International ALS/MND Symposium to discuss learnings and discoveries with other ALS researchers around the world.

BREAK THROUGH

Since the Ice Bucket Challenge in 2014, nearly \$20 million has been invested in Canadian ALS research at a time when it has the potential to make the greatest impact. Significant progress in ALS research is being made — researchers now believe that finding effective treatment options for ALS is now a matter of “when,” not “if,” and that research discovery is limited only by the amount of funding available to pursue it.

people with ALS and 7,500 control subjects, establishing a global resource of human data that no one country could build on its own. The four Canadian scientists participating in the project hail from different parts of the country and each brings experience in international consortia that have resulted in some of the most important genetic discoveries in the field. Project MinE represents their first cross-country collaboration and will enable Canadian DNA profiles to be contributed to the project. And this is just the beginning: Canada can play a meaningful role, but will require increased funding to invest in this initiative. Together, we can do our part.

Through a competitive peer-review process, ALS Canada funds the most promising Canadian research that will move the field forward faster. Read about the 20 research grants we funded in 2016 at www.als.ca/2016research



Approximately
1,000
Canadians

are diagnosed with ALS each year

At any time, there are approximately 2,500 to 3,000 Canadians living with ALS

Every day, two to three Canadians will die of ALS

80%

of people living with ALS die within two to five years of diagnosis

Only 5 to 10% have a hereditary link

\$6.8M

was raised by ALS Canada in 2016 thanks to donor and partner generosity

ALS CANADA FACTS



Often called the bankruptcy disease, the average cost of ALS to a family is between

\$150,000 and \$250,000*




In Ontario, the

WALK FOR ALS

raised more than \$2 million as part of a \$4 million nationwide total

*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.

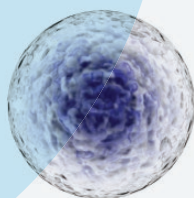




Amyotrophic Lateral Sclerosis (also known as ALS, Lou Gehrig's disease, or motor neuron disease) is a disease that gradually causes paralysis because the brain is no longer able to communicate with the muscles of the body that we are typically able to move at will. Over time, as the muscles of the body break down, someone living with ALS may lose the ability to walk, talk, eat, swallow, and eventually breathe.

175+ support groups took place across 15 communities

8 HIGHLIGHTS 2016



Research Spotlight

Among the 20 projects we funded in 2016 is one that is using stem cell technology to better understand and potentially treat ALS, while another is studying a new function for the gene most commonly linked to ALS development.

Through a competitive peer-review process, **ALS Canada** awarded **\$3.5 million in research grants in 2016, \$2.7 million of which was matched by the Brain Canada Foundation for a total of \$6.2 million.** Read more at www.als.ca/2016research



The first-ever all-party ALS Caucus meeting took place on Parliament Hill on October 4, 2016

3,500+

pieces of equipment were requested in 2016 – a 34% increase over 2015

1,100+

people living with ALS received services from ALS Canada in 2016

The gene **NEK1** was discovered to play a significant role in the development of ALS



Francis Drouin, MP for Glengarry–Prescott–Russell; Pam Damoff, MP for Oakville North–Burlington; Tammy Moore, CEO of ALS Canada; ALS Canada ambassador Carol Skinner and husband Travis Skinner

TOGETHER, WE CAN

Perspectives

"When I was diagnosed with ALS, I had to give up my career as an art therapist. I felt I'd lost everything, including my sense of purpose in the world. Becoming an ALS advocate gave me back meaning. For as long as I am able, I will continue to fight on behalf of our community."

CAROL SKINNER

ALS Canada Ambassador and advocate

"In recent years, progress in genetics has brought with it advances in our understanding of and potential treatments for neuromuscular diseases, including ALS. Genetic testing has become more commonly used for clinical and research reasons. Some patients and their families have expressed concerns about possible consequences of this testing, in terms of seeking insurance coverage or employment opportunities. We want all ALS patients and their families to feel comfortable fully engaging in clinical and research efforts without fear of repercussions, so that we can further discoveries and develop new therapies. This is why I have been advocating on behalf of ALS Canada to establish federal legislation that protects against genetic discrimination."



DR. BENJAMIN RITSMA

Physician in Physical Medicine and Rehabilitation & Clinical Fellow at the ALS Clinic, Sunnybrook Health Sciences Centre, Toronto

ADVOCACY

Helping others understand and respond to the needs of the ALS community

AS ALS ADVOCATES like Carol Skinner and Chris McCauley will tell you, the realities of living with ALS are devastating. Shock, rage, self-pity, frustration and depression are common – but often, so is an unwavering determination to speak out about the importance of research and support.

Advocacy is a priority for ALS Canada because of its ability to raise awareness and support within the public arena, to affect public policy on a national scale, and to make a meaningful difference in people's lives by helping Canadians to access services and other resources that ease some of the burdens of living with ALS.

Given the tremendous impact of an ALS diagnosis on a person's quality of life as the disease progresses, we are active in advocating for hospice and palliative care, which aims to lessen people's suffering through access to services and supports that increase comfort and improve well-being. As a member of the Quality End-of-Life Care Coalition of Canada and a participant in the Palliative Care Matters initiative that is working towards equal access and guaranteed standards in palliative care delivery across Canada, we work with other organizations to maximize our impact in advancing the national conversation on hospice and palliative care.

HOW WE ADVANCED ADVOCACY IN 2016

The Palliative Care Matters project, of which ALS Canada leadership is a part, released a national consensus statement and 20 specific recommendations to the government.

Bill S-201 that seeks to prevent genetic discrimination received a second reading in the House of Commons and was referred to the standing committee on justice and human rights.

Bill C-277 that calls for the development of a palliative care framework was introduced in the House of Commons.

The ALS Caucus, whose creation was spearheaded by ALS Canada, held its inaugural meeting on Parliament Hill on October 4, 2016.

A private member's motion, M-105, was introduced in the House of Commons calling on the government to invest in ALS research.

SPEAK UP

We believe the federal government has a role to play in providing direct and sustained investment in ALS research, which has very few avenues for funding support. Throughout 2016 we worked with our community to increase support on Parliament Hill for this tremendous need. A significant accomplishment was the creation of an all-party ALS Caucus that represents an established group of parliamentarians and senators who have come together to better understand the realities of ALS and opportunities to address them.

As a member of the Canadian Coalition for Genetic Fairness, ALS Canada is actively lobbying government to pass Bill S-201, which seeks to prohibit and prevent genetic discrimination.

Through a national advocacy committee, we work with provincial ALS societies and committed volunteers to advance the priorities we have identified for our collective advocacy efforts. Collectively, we are a strong voice working together to ensure that the needs of the ALS community do not go unheard.



In Tribute Mauril Bélanger

ALS Societies across Canada were saddened by the passing of Mauril Bélanger, MP for Ottawa-Vanier, in the summer of 2016. Diagnosed with ALS in late 2015, he took on the role of National Honorary Spokesperson for the 2016 WALK for ALS and was a committed champion for the ALS community. In the brief time we worked with Mr. Bélanger, we witnessed a tremendous outpouring of support from his family, friends and colleagues. Even after the disease took away his ability to speak, he used his voice to reiterate the need for research and a cure. We are grateful for your support, Mauril... rest in peace.

Volunteers
at the
WALK for ALS

TOGETHER, WE CAN

Perspectives

"We walk in memory of our dad, Thomas McKegney, who passed away in June 2016. In only a few short months, he went from needing the help of a cane to being completely dependent. Naturally, we wanted the best for him. For us, that meant keeping Dad at home and doing what we could to make him as comfortable as possible. ALS Canada provided us with the necessary equipment as it became available, and supported us with compassion and kindness along the way. All of these services were limited, of course, because of funding. We raise money so others living with ALS will be able to access critical support, and to contribute to ALS research because we are hopeful that one day soon, we will find a cure."



KIMBERLEY YOUNG

WALK for ALS top fundraiser and participant

"My husband and I started donating long before he was diagnosed. Initially, we chose the organization because it was a small charity that needed our financial support and that spent the money wisely. My planned gift to ALS Canada after Floyd passed away was a way to pay it forward for others. Floyd's condition changed quickly but it was comforting to know I could pick up the phone and talk to Sarah, the Regional Manager, when I had questions. Sarah is still a friend, and JR – the personal support worker I hired to provide in-home care for Floyd – has become family to me. And Floyd was able to stay at home until the end, which was his cherished wish."

DEIRDRE O'CONNOR

has made a gift to ALS Canada in her will

FUNDRAISING

*Making a brighter future
possible with your generosity*

THE GENEROSITY and commitment of thousands of donors and fundraisers make ALS Canada's work possible. Without government funding, we rely heavily on the support of individuals. Approximately 90% of our revenue is raised from events, monthly donations, annual gifts, and planned gifts. We are also grateful for the generous corporate donors and foundations who grant us vital financial support each year.

In 2016, we earned accreditation from Imagine Canada, in recognition of excellence in board governance, financial accountability and transparency,

In 2014, the Ice Bucket Challenge gave ALS a level of awareness that was long overdue. It was a tremendous gift, and we gave careful consideration to how to invest the unprecedented influx of donations to offer the greatest value to the community we serve, today and in the future. But by 2018, nearly all of the Ice Bucket Challenge funds will have been put to use, and ALS Canada will return to traditional funding levels at a time when effective ALS treatments are poised to become a reality – resulting in new avenues for research investment and a host of new needs for people living with the disease.

DO MORE

fundraising, staff management, and volunteer involvement. Meeting the highest standards for not-for-profit and charitable sector operational excellence in Canada signals to our donors and other stakeholders that they can have full confidence in the accountability and transparency of the organization. Together, we can do our part.

The need is therefore still great, and our donors will continue to play an important role in our shared journey to lessen the many burdens of an ALS diagnosis.

Thank You

We appreciate every gift, large and small. Donors who gave \$1,000 or more in 2016 are acknowledged on our website at www.als.ca/donors.

ALS Canada volunteers play a vital role at our office and at fundraising events, in the community and in our leadership. Thank you for the commitment and hours you dedicate to our shared cause.

WHO SUPPORTED ALS CANADA IN 2016?

The Brain Canada Foundation matched \$2.7 million in research grants.

Ontario WALK for ALS participants raised more than \$2 million as part of a \$4 million nationwide total.

Provincial ALS Societies contributed more than \$840,000 to the ALS Canada Research Program to support ALS research across the country.

More than 100 community-based fundraising events were organized by individuals and organizations who donated the proceeds to ALS Canada.

Nearly 200 individuals, families, and organizations generously donated new or used equipment to ALS Canada in 2016, at a value of more than \$250,000.

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, 2016, 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, 2016, ALS Canada held \$11.8 million in interest bearing cash, \$1 million in government bonds and \$5.5 million in corporate bonds, GICs and other financial instruments.

Statement of Financial Position

December 31, 2016

	General Fund	Research Fund	Tim E. Noël Endowment Fund	2016 Total	2015 Total
Assets					
Current					
Cash	\$ 11,841,899	\$ –	\$ 2,438	\$ 11,844,337	\$ 13,652,909
Short-term investments	1,370,116	–	388,776	1,758,892	1,516,560
Accounts receivable	296,959	322,783	–	619,742	820,405
Inter-fund transfers	(14,196,946)	14,289,084	(92,138)	–	–
Prepaid expenditures	87,221	–	–	87,221	27,482
	(600,751)	14,611,867	299,076	14,310,192	16,017,356
Long-term investments	3,369,571	339,352	1,000,924	4,709,847	4,988,006
Capital assets	249,041	–	–	249,041	32,434
	3,017,861	14,951,219	1,300,000	19,269,080	21,037,796
Liabilities					
Current					
Accounts payable and accrued liabilities	703,413	32,900	–	736,313	615,869
Current portion of deferred revenue	722,802	1,396,250	–	2,119,052	4,980,691
Current portion of research grants payable	–	3,294,633	–	3,294,633	3,056,389
Current portion of deferred lease inducement	–	–	–	–	27,191
	1,426,215	4,723,783	–	6,149,998	8,680,140
Long-term deferred revenue	886,640	535,837	–	1,422,477	1,487,199
Long-term research grants payable	–	5,058,315	–	5,058,315	4,729,726
	2,312,855	10,317,935	–	12,630,790	14,897,065
Commitments					
Net Assets	\$ 705,006	\$ 4,633,284	\$ 1,300,000	\$ 6,638,290	\$ 6,140,731
	3,017,861	14,951,219	1,300,000	19,269,080	21,037,796

Statement of Operations

Year ended December 31, 2016

	General Fund	Research Fund	Tim E. Noël Endowment Fund	2016 Total	2015 Total
Revenue					
Fundraising and donations	\$ 4,299,556	\$ 4,318,926	\$ –	\$ 8,618,482	\$ 13,017,685
Direct mail campaign	1,029,711	9,405	–	1,039,116	1,030,329
Interest and investment income	11,280	186,775	37,853	235,908	239,984
Unrealized gain/(loss) on investments	12,524	(23,884)	18,859	7,499	(19,110)
	5,353,071	4,491,222	56,712	9,901,005	14,268,888
Expenditures					
Research grants	–	3,488,454	–	3,488,454	8,057,763
Other research support	194	842,790	–	842,984	868,848
National federation services	43,705	–	–	43,705	85,225
Ontario client support services	2,308,098	–	–	2,308,098	1,809,489
Public awareness	228,486	–	–	228,486	331,343
Advocacy	112,095	–	–	112,095	108,756
Volunteer development	45,369	–	–	45,369	94,301
	2,737,947	4,331,244	–	7,069,191	11,355,725
Other					
Fundraising	1,690,974	–	–	1,690,974	1,901,139
Administrative	396,130	–	–	396,130	536,549
Governance	87,173	84,978	–	172,151	246,610
Bad debt expense	–	75,000	–	75,000	–
	2,174,277	159,978	–	2,334,255	2,684,298
	4,912,224	4,491,222	–	9,403,446	14,040,023
Excess of revenue over expenditures	\$ 440,847	\$ –	\$ 56,712	\$ 497,559	\$ 228,865

Statement of Changes in Net Assets

Year ended December 31, 2016

	General Fund	Research Fund	Tim E. Noël Endowment Fund	2016 Total
Balance, beginning of year	\$ 396,071	\$ 4,444,660	\$ 1,300,000	\$ 6,140,731
Excess of revenue over expenditures	440,847	–	56,712	497,559
Inter-fund transfers	–	56,712	(56,712)	–
Inter-fund transfers	(131,912)	131,912	–	–
Balance, end of year	\$ 705,006	\$ 4,633,284	\$ 1,300,000	\$ 6,638,290

SNAPSHOT OF 2016 REVENUE AND EXPENSES

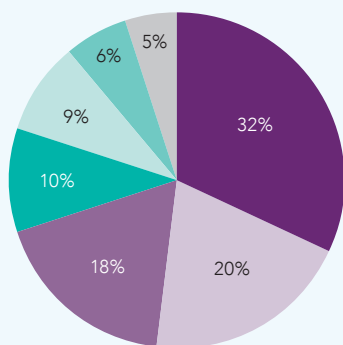
Revenue

ALS Canada's single largest source of revenue in 2016 was funds previously raised through the Ice Bucket Challenge. Our practice of following the deferred revenue accounting method means that even though these funds were raised in 2014, they were counted as revenue in 2016 when they were spent.

Excluding the Ice Bucket Challenge deferred revenue, in 2016 ALS Canada raised \$6.8 million. Our largest source of funds was the

WALK for ALS, a national initiative that in 2016 took place in more than 90 communities across Canada, including 32 Ontario communities that raised \$2 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 \$843,244 to ALS Canada in 2016 which includes 40% of their net WALK proceeds as well as additional giving.

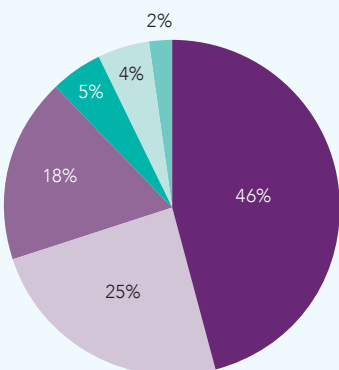
"Other fundraising" includes \$170,400 provided through the generosity of employees in federal government offices across Canada, who gave through HealthPartners, as well as the \$250,000 appraised value of equipment that was donated to ALS Canada in 2016, which was previously not reflected as revenue for the organization and is included as a corresponding expense for the equipment program. Also included are donations left in estates and wills, which totalled \$411,000 and large gifts from individuals, corporations and foundations totalling \$557,000.



2016 Revenue

- ALS Ice Bucket Challenge*
\$3,134,125
- Ontario WALK for ALS
\$1,998,797
- Other fundraising (donations and income)
\$1,793,828
- Direct mail
\$1,039,116
- From provincial societies (for research)
\$843,244
- Fundraising events
\$559,244
- Tribute and monthly giving
\$532,651

* Deferred revenue



2016 Expenses

- National research
\$4,331,437
- Support and services
\$2,308,099
- Fundraising
\$1,690,973
- Administrative
\$471,130
- Other charitable purpose
\$428,013
- Governance
\$172,151

Expenses

Research

In 2016, ALS Canada awarded \$3.5 million in new research grants. We accounted for the full financial commitment of these grants in 2016, although some will be paid out over multiple years. An additional \$843,000 was used to support the ALS Canada Research Program and the broader ALS research community in Canada, including our initial commitment of \$150,000 for Canada's involvement in Project MinE, an international initiative that we will continue to support in future years.

Our research expenditures do not show an additional \$2.7 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 2016 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 million providing direct service to clients 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 – for example, advocacy and visibility with government resulted in increased financial support starting in 2016 for family members who took time off work to care for a loved one.

Fundraising

Our revenue and the expenses associated with generating it are analyzed regularly to ensure our cost of fundraising is controlled. In 2016, our cost of fundraising was 25%, 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 meets in person four times a year 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.

WHAT HAPPENED TO THE MONEY RAISED THROUGH THE ICE BUCKET CHALLENGE?

The Ice Bucket Challenge that dominated headlines and social media feeds in the summer of 2014 was a tremendous gift to the ALS community, raising awareness and unprecedented donations – more than \$17 million in Canada alone. As the grateful recipients of these donations in Canada, ALS Societies across the country were faced with the responsibility of stewarding the funds in ways that would maximize the benefits to people living with and affected by ALS, today and in the future.

Of the money raised through the Ice Bucket Challenge, \$11.5 million, which includes funds generously donated by each of the ALS Societies across Canada, was directed to the ALS Canada Research Program for research grants and initiatives: \$7.1 million in 2015, \$2.9 million in 2016, and \$1.5 million for future commitments in 2017 and beyond. The Brain Canada Foundation matched an additional \$10 million for a total research investment of \$21.5 million – proof that by working together we can do much more!

An additional \$4.4 million was directed to provincial services and support, including \$1.9 million in Ontario of which \$501,175 has been invested as of December 31, 2016. These investments have been informed in part by the experiences of the people we serve to help us strengthen the support they receive from us in the future. Many of these enhancements are being rolled out in 2017 following thoughtful review and planning in 2015 and 2016.

ABOUT ALS CANADA

OUR VISION is to find a treatment for ALS. It is unwavering and keeps us focused as we look to our future. By 2024, we want ALS to be a treatable disease.

OUR MISSION is our everyday journey as an organization: Together with our Provincial Partners – supporting Canadians living with ALS and investing in research to make ALS treatable, not terminal.

Founded in 1977, the ALS Society of Canada (ALS Canada) and our provincial partners are dedicated to supporting Canadians living with ALS and investing in research to make ALS a treatable, not terminal, disease. 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 in new areas of research where we are well-positioned to have an impact. Support for the ALS Canada Research Program is made possible by the generosity of donors, the ALS Societies across Canada, and the Brain Canada Foundation (with financial support from Health Canada).

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. We help to fill the gaps between the healthcare system and needs of people living with ALS.

ALS Canada advocates federally, provincially and locally for better government support and access within the healthcare system for people touched by ALS.

ALL OF US

ALS Canada is privileged to work alongside and support a passionate community of people who share our cause. This report pictures just a few of them, whom we have identified wherever possible.

On Our Cover

(From left to right)

Top Row

Wendy Corber and son Jonathan
Dr. Jeehye Park
Participants in the WALK for ALS
The Peacock family
Carol Skinner
Eddy Lefrançois and Jay Johnston

Second Row

Volunteers at the WALK for ALS
Dr. Christen Shoesmith
Jacqui Devine
Veronique Belzil
Tom Dando and Denis Blais

Third Row

Justin Landry
Norm and Chris McCauley
Darlene and Dr. Jeff Sutherland
Participants at the WALK for ALS
Participant at the WALK for ALS
Volunteers at the WALK for ALS

Bottom Row

Kinga Repic
A young participant at the
WALK for ALS
Dr. Guy Rouleau
Participants at the WALK for ALS
Dr. Sanjay Kalra



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Amyotrophic Lateral Sclerosis Society of Canada

Charitable Registration Number:

10670-8977-RR0002