



# GAINING MOMENTUM

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## WE COULDN'T DO IT **WITHOUT YOU.**

Thank you for supporting the ALS community. Because of your generous financial contribution you are helping Canadians manage their journey through ALS and funding critical research to make ALS a treatable, not terminal disease.

Due to the space constraints, the acknowledgments reflect a donation of \$1000 or more in 2015. We honour our donor requests to remain anonymous, therefore these donors will not be listed in this report. ALS Canada is grateful to all of our donors at all levels of support.

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# MESSAGE FROM ALS CANADA CHAIR & CEO



Geneviève Bertrand, Chair, ALS Canada Board of Directors

ALS Canada had a break-through year in 2015 with solid progress in all areas of our organization.

We constituted a Client Services Advisory Council (CSAC) to help inform and guide the Board's long-term vision for Client Services. This Council possesses broad skills and expertise across the healthcare, government and medical equipment sectors and includes the valuable experience and voice of caregivers and people living with ALS. It follows on our commitment to continuously improve the service and support we provide to Ontarians living with ALS and their caregivers. As we work towards finding a treatment for ALS, we are committed to ensuring we have the capacity and resources to meet the needs of people living with ALS, today and in the future.

It was our continuing pursuit of putting the needs of the ALS community at the forefront where we saw our efforts come full circle around the issue of the Compassionate Care Benefit (CCB). The federal government extended the CCB so that caregivers can claim up to \$13,624 in benefits to relieve some of

the financial burden ALS incurs on families. This was achieved through many years of collaboration and leadership of ALS Canada working with the Societies across Canada, volunteers and people living with ALS who spoke passionately with members of Parliament to communicate the realities of families dealing with ALS.

Volunteers were instrumental in gaining momentum in our fundraising and awareness efforts across the province. The WALK for ALS raised \$1.9 million in Ontario and a total of \$4 million nationally. We thank all the volunteers who donated their time generously to our signature events and to their own community fundraisers. We were also pleased to engage a new group of volunteers with the launch of the ALS Canada Ambassador Program; people from the ALS community who raise awareness by sharing their personal stories on their experiences with ALS.

Partnerships with both the Brain Canada Foundation and the federation of ALS Societies across Canada supported our momentum towards meeting our vision of making ALS a treatable, not terminal disease by



ALS Canada Board of Directors



Tammy Moore, CEO, ALS Canada and Eddy K. Lefrançois, ALS Canada Ambassador

2024. We were able to leverage our national ALS Canada Research Program to announce an historical investment of \$15 million into the most promising, peer-reviewed Canadian ALS research across the country. Our thanks go out to all the donors who contributed funds to make this year so successful.

We have great appreciation for the Board members who come from across Canada and generously share their expertise to lead our complex organization, their contributions are significant as we gain momentum. It is with sadness that we said good bye to Melanie York, a Board member, passionate advocate, and cherished member of our team who passed away earlier in the year.

Nurturing relationships and building networks amongst local, provincial and international ALS stakeholders continued to be one of our priorities. This year, CEO, Tammy Moore, joined the International Alliance of ALS/MND Associations Board of Directors, connecting ALS Canada to the world-wide community of ALS organizations. The Alliance functions as a forum for

the exchange of information on all aspects of the disease, including research and management of client care and has proven to be a strong network to keep informed for advances and opportunities for ALS on a global stage.

We are proud of the work we have achieved together as we support Canadians and serve Ontarians living and affected by ALS and the investments in ALS research in Canada. We will continue the momentum to make ALS a treatable, not terminal disease.

Sincerely,

**Geneviève Bertrand, Chair**

**Tammy Moore, CEO**

## ALS CANADA LEADERSHIP

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ALS Canada representatives:  
Tammy Moore, CEO  
Rick Morgan, ALS Canada Board Member





# STEPPING FORWARD TO PROVIDE QUALITY CARE AND SERVICES.

**YOU** ARE MAKING A **DIFFERENCE** TO HUNDREDS OF FAMILIES ACROSS ONTARIO.

Brian Heaney with Joanna Oachis, ALS Canada Regional Manager

# ENABLING ACCESS TO SERVICES

ALS Canada's mission for client services is to deliver consistent quality programs and services to people living with ALS across Ontario throughout the course of the disease. With your help, we were able to connect to the ALS community through the provision of an equipment program, in-home visits, specialized group programs, and education and advocacy initiatives at the local, provincial, federal and international levels.

ALS is a progressive disease. As the disease becomes more debilitating, the need to manage the symptoms increases. In 2015, 1,041 clients were registered with ALS Canada. From this group, over half (606 clients) of ALS Canada clients were given support through the equipment loan program and financial assistance to lease and rent equipment. We provided equipment like wheelchairs, commodes, scooters, beds and Hoyer lifts to Ontarians to help them maintain a quality of life. In total, we fulfilled 1,793 requests for medical equipment and assistive devices for clients across Ontario. It is because of your financial gifts, equipment donations and in-kind contributions that we could provide this service. In total, we received equipment donations valued at over \$185,000.

A large part of providing quality care is in the services we offer. ALS Canada Regional Managers provided in-home visits and conducted support groups with clients and caregivers in over 150 communities throughout Ontario. The value of these services is immeasurable to people living with ALS, families and caregivers. Support group programs allow the ALS community to share information and express their feelings in a nurturing, safe environment. They show families, clients and caregivers that they are not alone in this journey. Thank you for helping connect the community together across the province.

One of our mandates is to facilitate access and support to resources and services that help the ALS community manage their journey with ALS. Our goal is to ease the hardships caused by ALS by ensuring each client and family is able to access services to meet their needs as they navigate the realities of ALS - physically, emotionally and financially. As a team, we take a collaborative approach to help families work through the complexity of our healthcare system, ensuring that they had access to high quality, timely services from healthcare experts. We advanced community partnerships to aid in meeting the needs of Ontarians living with ALS by forming strong partnerships and relationships with ALS

Clinics, CCACs and hospice and palliative care organizations. We partnered with some CCAC team members on joint in-home visits to provide clients with more integrated care, working together to ensure client needs were met. We look forward to building this throughout Ontario.

We further drove momentum around awareness and education and distributed educational materials that supplemented the information already provided by a client's neurologist and other healthcare team members to clients and healthcare experts. We focused on continuing to work with the healthcare and social systems to be there every step of the way as clients live through the varying stages of ALS.

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## WORKING TOGETHER TO RAISE FUNDS FOR CLIENT SERVICES

Our team spent 2015 cultivating relationships with members of the ALS community and donors to raise funds to directly help clients living with ALS in Ontario. In Ontario alone, 32 communities participated in the WALK for ALS where donors raised over \$1.3 million to support client services.

Further funding was given through the generosity of foundations and corporations.

### **The Pottruff Family Foundation**

- Covered transportation costs to assist families' travel to and from medical appointments and the purchase of six tilt commodes.

### **Scarborough Centre for Health Communities**

- Supported caregiver wellness activities such as stress reduction, taking care of oneself and coping strategies. Further expenditures to be made in 2016.

### **Capital One**

- Purchased one bed, six mattresses, six easy lift chairs and an electric wheelchair.

### **HOPE Ottawa Carlton**

- Donated funds from their 2015 Volleyball Summerfest for a pilot caregiver respite program in 2016 for clients living in Ottawa.

### **Community Foundation of Ottawa**

- Provided caregiver support and training sessions for 2016 in the Ottawa area.

### **Harold Ballard Foundation**

- Purchased three easy lift chairs, one stair lift and a tilt commode with further purchases to be made.





# ALS CANADA CLIENT SERVICES BY NUMBERS: OUR ACHIEVEMENTS



**343** new clients registered in **2015** for a total of **1,041** registered clients



We conducted **1,077** home visits and facilitated ongoing communication with thousands of clients by phone and email



**152** support groups held for clients and/or caregivers in **over 15** communities throughout Ontario



Initiated new client and caregiver support groups in **Kingston** and **Niagara Falls**



**1793** pieces of equipment for **606** clients



Initiated a new client only support group in **Hamilton** and a meet and greet group with **McMaster** students and ALS clients and families



Continued onsite attendance in the weekly ALS Clinic at **Sunnybrook Health Sciences Centre** in Toronto



Active participation by Regional Managers in **hospice palliative care committees** across the province



Held numerous **educational sessions** and **in-services** for healthcare professionals and caregivers, including **3** transfer training sessions for caregivers in 2015 in Ottawa

## THE FUTURE OF CLIENT SERVICES

ALS Canada has gained momentum in the area of client services. We established a renewed Client Services Advisory Council (CSAC) to provide input and perspectives towards ALS Canada's client services strategy and operation plans so that we can improve clients' and families' journey with ALS in Ontario and continue to be leaders in the ALS community.

We thank the outgoing Support Services Council for all their efforts and generous contributions. As we move forward, we look to the CSAC, who possess broad skills and expertise in the healthcare, government and medical equipment sectors, to provide future guidance for the immediate and long-term vision of ALS Canada.

However, we still require your continued support to build on the momentum achieved in 2015. When ALS becomes a treatable disease, we will need to ensure services and equipment programs are sustainable to help the entire ALS population across Ontario. Thank you for your generous contributions and for helping make a difference to Ontarians living with ALS across the province.

## ALLAN BRADSTREET

### LIVING WITH ALS



Walking our dog Buddy was always part of my daily routine, until the day I fell with my walker and had to get two construction guys to get me up off the sidewalk. After three years with ALS, I figured that was the last time I would be able to do it and it would be another 'job' my wife would have to take on. That next week I went to an ALS Canada support group meeting and it was suggested I get a scooter. It wasn't something I could afford but was told ALS Canada could lend me one. Literally one day after the application went in they called to deliver it. The gentleman showed my wife how to put it together and take it apart, and now she says she can do it with her eyes closed. Now I take Buddy for two walks per day!

I can't say thank you enough (even though I try all the time).





# PUSHING THE FIELD OF ALS RESEARCH FORWARD.

YOU ARE **PAVING THE WAY** TO MAKE ALS **TREATABLE**, NOT **TERMINAL**.

# THE ALS CANADA RESEARCH PROGRAM AIMS TO ACCELERATE RESEARCH IMPACT THROUGH A COMPREHENSIVE NATIONAL PROGRAM FOCUSED ON TRANSLATING SCIENTIFIC DISCOVERIES INTO TREATMENTS FOR ALS AND FOSTERING CANADA'S STRONG AND NETWORKED ALS RESEARCH COMMUNITY TO BUILD CAPACITY AND COLLABORATION.

Everyday, we push forward in efforts to continue to elevate the ALS Canada Research Program, investing in the best science that offers the most promise to slow down ALS or even stop it. We are driven to improve the lives of the 3,000 Canadians managing their journey through ALS, and who are losing their ability to speak, walk and eventually breathe because of this disease. Research is the pathway to change the course of ALS. With your continued support, you are helping to make ALS treatable, not terminal.

In 2015, because of the generosity and dedication from ALS Societies across Canada, our donors and ALS Canada's partnership with Brain Canada, we were able to invest \$15 million in ALS research across Canada. To put that investment into perspective, this influx into ALS research represented a 10-fold increase from what we were able to historically invest on an annual basis.

The research funded was reviewed by a panel of ALS experts, who were brought together to judge the projects with the mandate to invest in the research that will move the field forward in the quickest time frame possible. We focused on building momentum by placing funds into the hands of present and future leaders in ALS research.

In 2015, the research program funded 56 investigators at 15 universities in seven provinces across Canada. All are working to uncover answers around how we can diagnose ALS earlier; what role do various proteins play to improve treatment options for people living with ALS; and ultimately how can we slow or stop the progression of the disease.

# WORKING TOGETHER RESEARCH INVESTMENT \$15 MILLION



## Team Julien

### Université Laval

Preclinical and clinical studies with withanolides: therapeutic effects, molecular signatures and biomarkers

**\$2.5 million over 3 years**

## Team Kalra

### University of Alberta

Novel MRI biomarkers for monitoring disease progression in ALS

**\$2.9 million over 5 years**

## Team Kong

### University of Manitoba

Selective knockdown of misfolded SOD1 as a therapy for amyotrophic lateral sclerosis

**\$1.6 million over 5 years**

## Team Korngut

### University of Calgary

A randomized controlled trial of pimozone in subjects with ALS

**\$500,000 over 3 years**

## Team St George-Hyslop

### University of Toronto

Discovery of therapeutic targets for FUS-dependent forms of ALS

**\$1.4 million over 5 years**

## Team Vande Velde

### Université de Montréal

Regulation of the stress granule proteome and transcriptome by TDP-43 in ALS: biomarkers and therapeutic targets

**\$1.7 million over 5 years**

## Dr. François Berthod

### Université Laval

Study of the impact of glycation on ALS using an in vitro tissue-engineered model of spinal cord

**\$100,000 over 2 years**

## Dr. Martin Duennwald

### Western University

RGNEF modulates protein misfolding in ALS

**\$100,000 over 2 years**

## Dr. Heather Durham

### McGill University

Epigenetic mechanisms underlying dendritic atrophy in ALS

**\$100,000 over 2 years**

## Dr. Charles Krieger

### Simon Fraser University

Use of bone marrow cells to deliver single chain antibodies in ALS

**\$100,000 for 1 year**

## Dr. Blair Leavitt

### University of British Columbia

Muscle-targeted therapy for ALS

**\$100,000 for 1 year**

## Dr. Peter McPherson

### McGill University

Regulation of endosomal membrane trafficking by C9ORF72 in ALS

**\$100,000 for 1 year**

## Dr. Pier Jr Morin

### Université de Moncton

Identification of circulating non-coding RNAs with diagnostic relevance to ALS patients using a unique extracellular vesicle capture method

**\$100,000 over 2 years**

## Dr. Alex Parker

### Université de Montréal

Investigation of the innate immune system and motor neuron degeneration in genetic models of ALS

**\$100,000 over 2 years**

## Dr. Janice Robertson

### University of Toronto

Characterizing the C9ORF72 protein interactome for identifying novel pathogenic pathways in ALS

**\$100,000 over 2 years**

## Dr. Fabio Rossi

### University of British Columbia

The role of peripheral inflammation in ALS: an exploratory study

**\$100,000 over 2 years**

## Dr. Amir Sanati Nezhad

### University of Calgary

Novel microfluidic platform for investigating axonal sprouting in motor neurons

**\$100,000 over 2 years**

## Dr. Christine Vande Velde

### Université de Montréal

Misfolded SOD1 species in ALS pathogenesis

**\$100,000 over 2 years**

## Dr. Melanie Woodin

### University of Toronto

Synaptic inhibition in the motor cortex of an ALS mouse model

**\$100,000 over 2 years**



# HOW TO FIND A TREATMENT FOR ALS



4 RECIPIENTS



ALS Canada  
Bridge Grants  
- 2 year  
\$800,000

**Dr. Neil Cashman**  
**University of British Columbia**

Molecular interactions between TDP-43 and misfolded wild-type SOD1: implications for sporadic amyotrophic lateral sclerosis  
\$200,000 over 2 years

**Dr. Avi Chakrabarty**  
**University of Toronto**

Role of TDP-43 in regulation of stress granules in ALS: biomarkers and therapeutic agents  
\$200,000 over 2 years

**Dr. Jasna Kriz**  
**Université Laval**

Glia-neuron crosstalk in early amyotrophic lateral sclerosis  
\$200,000 over 2 years

**Dr. Victor Rafuse**  
**Dalhousie University**  
Characterization of the mechanisms underlying exercise induced strengthening of the neuromuscular junction  
\$200,000 over 2 years



2 RECIPIENTS



ALS Canada - Brain  
Canada Career  
Transition Awards  
\$740,000

**Dr. Gary Armstrong**  
(supervisor: Dr. Pierre Drapeau)

**Université de Montréal**  
Mechanisms of glutamatergic neuronal dysfunction in genetic models of ALS  
\$425,000 over 5 years

**Dr. Chantelle Sephton**  
(mentor: Dr. Jean-Pierre Julien)

**Université Laval**  
Mechanisms of synaptic dysfunction in amyotrophic lateral sclerosis  
\$315,000 over 3 years



3 RECIPIENTS



Fellowships  
1 - 3 years  
\$530,000

**Dr. Marvin Chum**  
(supervisors: Dr. Teneille Gofton, Dr. Christen Shoesmith)

**Western University/ London Health Sciences Centre**  
Palliative care and respiratory support of patients with ALS  
\$200,000 over 2 years (clinical research)

**Dr. Jacquelyn Cragg**  
(supervisors: Dr. Neil Cashman, Dr. Marc Weisskopf)  
**University of British Columbia**  
Etiology and progression of amyotrophic lateral sclerosis: the role of military service, trauma, and prescription drug use  
\$165,000 over 3 years

**Dr. Matteo Da Ros**  
(supervisor: Dr. Derrick Gibbings)  
**University of Ottawa**  
Unbiased determination of pathways affected by ALS-linked stress granules and their elimination by autophagy  
\$165,000 over 3 years



4 RECIPIENTS



ALS Canada  
Bridge Grants  
- 1 year  
\$400,000

**Dr. Heather Durham**  
**McGill University**  
Dendritic attrition in amyotrophic lateral sclerosis  
\$100,000 for 1 year

**Dr. Peter McPherson**  
**McGill University**  
Endosomal membrane trafficking in neurodegenerative disease  
\$100,000 for 1 year

**Dr. Christopher Pearson**  
**University of Toronto**  
Unusual nucleic acid structures in C9orf72-related ALS/FTD repeat instability  
\$100,000 for 1 year

**Dr. Chantelle Sephton**  
**Université Laval**  
Effects of amyotrophic lateral sclerosis-linked FUS mutations on synaptic function  
\$100,000 for 1 year



2 RECIPIENTS



Doctoral  
Research Award  
- 3 year  
\$150,000

**Éric Martineau**  
(supervisor: Dr. Richard Robitaille)  
**Université de Montréal**  
Targeting the regenerative function of glial cells at the neuromuscular junction in amyotrophic lateral sclerosis  
\$75,000 over 3 years

**Maneka Chitiprolu**  
(supervisor: Dr. Derrick Gibbings)  
**University of Ottawa**  
Mechanisms eliminating stress granules by autophagy  
\$75,000 over 3 years

## ADDITIONAL RESEARCH INVESTMENTS (\$670,000):

Canadian Neuromuscular Disease Registry  
Clinical Practice Guidelines/Canadian ALS Research Network  
Travel Awards  
Sponsorship of meetings

## 2015 UPCOMING RESEARCH GRANTS (\$348,400):

Clinical Research Fellowship  
Clinical Management Grant





Your donations helped leverage collaborative partnerships amongst the best in the field. The ALS Canada - Brain Canada Arthur J. Hudson Translational Team Grant, which represents the single, largest ALS research competition in Canadian history, awarded teams of researchers across multiple academic institutions over \$10 million in funding. We funded an additional 13 Discovery Grants for novel, 'outside-the-box' ALS research, and gave fellowships to promising ALS researchers to solidify an infrastructure of support for continued ALS research. Also, for the first time, we invested in a research grant aimed at helping manage the symptoms of the disease and improve the lives of Canadians with ALS.

The future of the field of ALS is promising. We witnessed this first hand at the 11th annual ALS Canada Research Forum. This event brings together the national ALS research community to share ideas, form collaborations and work together as a unified group to continue reaching our vision to make ALS treatable by 2024. This year the ALS Canada Research Forum made history in representing the highest level of



attendance since its inception with 110 attendees. It is even more evident that ALS researchers are committed and resolute in their goal to stop this complex disease.

To stop ALS, we will need your help. The investments made in 2015 will deliver results in the next three to five years. Starting in 2017, critical funding will be needed to build on the momentum of the discoveries from this year's investments, in support of what today's research will bring to the future of ALS. It will take each and every one of us to beat this disease.

Thank you for your support over the past year and your continued commitment to the ALS Canada Research Program.

## UNRAVELING ALS TDP-43 AND C9ORF72

This year saw promising new leads in understanding the normal functions of arguably the two most important ALS proteins: TAR DNA-binding protein 43 (TDP-43) and C9ORF72. Determining how these normal functions are disrupted in ALS has been sought after for years and has resulted in new lines of potential therapy that will now be tested in laboratory models of the disease with hopes of future effect in humans.

## INTERNATIONAL COLLABORATION

In 2015, more genetic causes of ALS were discovered, including TANK binding kinase 1, an intriguing new target that will inevitably help in our understanding of how ALS is caused. Its identification was the result of a multi-national collaboration that provided collective data sufficient to declare it as a bona-fide ALS gene. More and more of these consortia are taking advantage of shared resources and knowledge to work together on solving problems that can't be tackled alone. As the world shrinks, our chances of breakthroughs in ALS grow.



# FUNDING THE ALS CANADA RESEARCH PROGRAM

Support for the ALS Canada Research Program is made possible by the generosity of donors and the ALS Societies across Canada, who donate 40% of the proceeds from the WALK for ALS as well as additional support throughout the year from other fundraising and donor initiatives. In 2014, the ALS Societies across Canada gave \$11.5 million from the funds raised through the ALS Ice Bucket Challenge towards the research program, allowing us to double the investment through Brain Canada and the federal government's Canada Brain Research Fund.

To learn more about the ALS Canada Research Program, please visit **ALS.CA**.

## THE ALS CANADA RESEARCH PROGRAM BY NUMBERS: OUR ACHIEVEMENTS



**34** projects funded representing **56** investigators at **15** universities in **7** provinces



Launched **4** unique ALS Canada Research Program monthly webinars



First time research carries over to client care with the launch of the new **Clinical Management Grant**



**\$15 million** invested in ALS research across Canada



Dr. David Taylor, Director of Research



## DR. CHRISTINE VANDE VELDE

**SCIENTIST** UNIVERSITY OF MONTREAL HOSPITAL RESEARCH CENTRE (CRCHUM) AND ASSOCIATE PROFESSOR AT THE DEPARTMENT OF NEUROSCIENCES, UNIVERSITÉ DE MONTRÉAL

ALS Canada has been a major supporter of my team. My first grant was a CIHR Neuromuscular Partnership grant in 2007, of which ALS Canada was one of the founding partners. This early support allowed me to hire a research technician and equip the lab with all the basics immediately. As a result, we were able to launch quickly.

As time progressed, another member of my team also received funding from ALS Canada, allowing a talented graduate student to stay focused on ALS research. The investments made in our lab, through Bridge Grants, have enabled the lab to

keep going. The Discovery Grants we received helped us to explore truly novel directions into mechanisms that could lead to ALS and thus yield new therapeutic targets.

Most recently, in 2015, we were one of the recipients for the Arthur J. Hudson ALS Canada-Brain Canada Translational Team Grant. This grant will allow us to really explore in depth a new direction in ALS research and cross from the lab to the clinic and back again. We are very excited to get this going and extremely grateful to ALS Canada and donors for their continued support.



# RAISING OUR VOICES FOR CHANGE.

**YOUR** SUPPORT HELPED **REFORM** THE  
COMPASSIONATE CARE BENEFIT (CCB).

Brian Parsons, Tammy Moore and Dr. David Taylor



In April of 2015, the Government of Canada placed into the federal budget a reform consideration to increase the CCB from six to 26 weeks. This benefit is essential to support caregivers and alleviate some of the financial burden ALS families face with an ALS diagnosis. It is because of your financial support that our team was able to travel and lobby Parliament Hill on behalf of the ALS community.

## LOBBYING FOR REFORM

Since 2013, ALS Societies across Canada have participated in over 100 meetings lobbying for reform to extend the CCB from six to 35 weeks and for eligibility upon diagnosis. ALS is nicknamed the 'bankruptcy disease' because the cost to an average family over the course of the disease ranges from \$150,000-\$250,000. As ALS progresses, families are faced with significant financial burdens to maintain an appropriate level of care and quality of life for their loved one. Obtaining support from the Compassionate Care Benefit is extremely important.

The ALS Canada advocacy team, CEO Tammy Moore, ALS patient advocate Brian Parsons and Dr. David Taylor, Director of Research, brought the stories of the 3,000 Canadians living with

ALS to Parliament Hill. They asked members of Parliament to match the support that Canadians across the country had shown for people living with ALS and their families.

## CULTIVATING RELATIONSHIPS ON PARLIAMENT HILL

Our efforts culminated in a meeting with the Minister of Finance, Joe Oliver, on March 27, 2015 and other MPs to reinforce the need to extend the CCB, weeks before the Federal Budget was tabled on April 21st.

## GETTING INVITED TO ATTEND THE FEDERAL BUDGET LOCK-UP

On April 21, 2015, ALS Canada CEO Tammy Moore was invited to attend the federal government's

budget lockup announcement, which gives invitees a preview of the budget prior to being made public in the House of Commons. It was during this announcement that the impact of our collective efforts came to fruition. For the first time in the history of our organization, the federal government placed into budget the extension of the CCB with a commencement date of January 3, 2016.

Today, caregivers can now claim up to \$13,624 over a 26-week period in benefits, where previously it was \$3,144. The benefit can also be taken within an expanded period of 52 weeks and can be shared between family members.

We could not have played a role in changing this benefit without your support.

Our team is building on the momentum from this achievement, continuing to work with members of Parliament and the Government of Canada. The goal is to improve access to the CCB and get the extension to 35 weeks with eligibility upon diagnosis for people living with ALS. We continue to stay the course to champion for ALS families across the country.

## CAROL SKINNER

### ALS ADVOCATE



Advocating for ALS is so important as ALS is a terribly underfunded illness. When you are given a diagnosis of ALS, it comes without hope. For those of us living with ALS we need to know that we are not alone, and that society and governments understand there is no time to waste.

I was invited to become involved with advocacy efforts with ALS Canada when I was asked to be the lead walker for the Ottawa WALK for ALS in June 2015. I have to admit I was nervous. However, Tammy Moore and Dr. David Taylor met with me and my husband and assured us that I had a valuable story to tell and I just needed to be myself!

From there, I was asked to speak at the Compassionate Care Benefit announcement with the Minister of Health and the Minister of

State for Social Development, as well as at the Ottawa flag raising ceremony to proclaim June as ALS Awareness Month with Mayor Jim Watson. I also had the opportunity to share my story at ALS Canada's press conference regarding the investments made towards ALS research at the Montreal Neurological Institute in November 2015.

I feel so privileged and honoured to be an advocate on behalf of ALS Canada. Due to my illness I was forced to quit my job immediately upon diagnosis. At that time I was trying to focus on me and my family, but felt something was missing. Being an advocate for ALS has brought back purpose and meaning to my life. Through advocacy, I found a way back to myself and who I am as a person. I could not get through this without the support of ALS Canada. For that I am so grateful.



# FUNDRAISING WITH HEART.

YOU ARE **INSPIRING** THE ALS COMMUNITY.

Dr. Jeff Sutherland, Darlene Sutherland and their WALK for ALS team



You are inspiring the ALS community to rally together with one powerful voice that says *it's time to get everyone listening*. With the right commitment to research funding, we can develop treatments to slow, or even stop the progress of the disease after diagnosis. With sufficient resources, we can reach out to each and every client who requires support. Donors like you keep the momentum strong. The passion you bring is tangible.

The journey is never easy. A diagnosis of ALS brings many unwanted challenges. With an average prognosis of two to five years, time matters. Every successful fundraising initiative matters. The sooner we can begin clinical trials to help moderate symptoms, the closer we will be to making ALS treatable, not terminal. The sooner we can provide support to all clients with ALS, the closer we will be to changing the face of this devastating disease. Our generous supporters understand the urgency of keeping the pressure on to do more. They are making a profound difference to improve the lives of clients and families coping with ALS.



## FUNDRAISING EVENTS

In 2015, individuals and organizations across Ontario generously contributed to fundraising events, raising over \$2.6M. Thank you for each step you took in the WALK for ALS events across Canada; for every push of your bicycle pedal at the Jim Hunter ALS Cycle for a Cure; for each ounce of strength you mustered during the Bombardier Plane Pull for ALS; for every golf swing you made at the ALS Canada Charity Golf Classic; for every stride you took hiking trails; and for every barbecue, block party, dance-a-thon and Ice Bucket Challenge you participated in. You gave hope to everyone touched by ALS.



## ALS CANADA FUNDRAISING INITIATIVES BY NUMBERS: OUR ACHIEVEMENTS



Canadians coast to coast took to the streets in **93 WALK locations** across the country, raising an amazing **\$3.8M** for research and provincial programs



WALK for ALS raised **\$1.9M** in Ontario



**670** teams in Ontario participated in the WALK for ALS in memory or in support of loved ones and friends



We are humbled by all the big-hearted donors who contribute to ALS Canada and champion the cause. These are individuals, foundations, and corporations who contribute by funding a specific project, workplace or in memory of a loved one. Thank you for your generosity, involvement and altruism.

## PLANNED GIVING

Families across the country gave to ALS Canada through planned giving. Leaving a gift in a will or other vehicle such as a life insurance policy or stocks is a way to leave a meaningful legacy that promises to improve the lives of people living with ALS in the future. In the future we invite you to consider leaving a gift in your will.



## CIRCLE OF HOPE MONTHLY GIVING PROGRAM

Monthly giving provides stable, year-round funding that enables our organization to respond quickly to promising initiatives. In total, monthly donors gave \$153,000 to provide sustainable support to ALS Canada. This important program is a cost-effective way to give and provides stable, ongoing revenue to support our charitable work. Please consider becoming a Circle of Hope monthly donor.

## DR. MARISA FINLAY

MONTHLY DONOR



My dad Maurice was only 37 when he found out he had ALS. He was diagnosed five years after losing his own father to the disease.

Ten years ago, I started supporting ALS Canada as a monthly donor. It's vital for ALS researchers to be able to count on month-to-month funding as they do their work to develop treatments..

With my family history, I myself have a 50/50 chance of getting ALS. As you can imagine, I'm cheering on researchers from the sidelines. I want to know that they are getting the support they need to make changes within my lifetime. I am proud to be a monthly donor because I know I'm playing an important role in the research being done into ALS. Together, we can beat ALS.



# 2015 MANAGEMENT DISCUSSION & ANALYSIS

ALS Canada is pleased to report that 2015 was a successful year in fulfilling the mission of the organization and the outcome of the fundraising efforts to support the work.

## DONATIONS RECEIVED FROM THE ALS ICE BUCKET CHALLENGE

In 2015, ALS Canada received an additional \$218K on behalf of the ALS Societies across Canada from ALS Ice Bucket Challenge donations, further adding to the more than \$17 million collected from this initiative in 2014. In total, from the ALS Ice Bucket Challenge, more than \$11.5 million has been directed to the ALS Canada Research Program which includes the funds generously dedicated by each of the ALS Societies across Canada.

## CHARITABLE PURPOSE

### Research

In 2015, \$15 million was awarded to ALS grants and research initiatives; this included the matched funds from Brain Canada and their public-private partnership with the Government of Canada.

ALS Canada contributed \$8.1 million in new research grants. This increase from 2014 is largely due to \$7.0 million of awards from the ALS Ice Bucket Challenge funds (with an additional \$6.0 million match from Brain Canada). In addition, a further \$670K was spent by ALS Canada to support the Canadian ALS research community and program.

### Client Services

ALS Canada fulfilled its mission to support clients living with ALS in Ontario and provided over \$800K of equipment and direct client services of \$740K. This was supported by an investment of \$224K of Ice Bucket Challenge during 2015 to acquire new assistive devices and equipment. During the year, a robust plan was developed for the future use of Ice Bucket Challenge funds set aside to be invested in the equipment program as well as improvement and restructuring of services for our clients and their families.

### Awareness and Advocacy

ALS Canada has a responsibility for public awareness and federal advocacy, overall \$440K was invested in these areas of charitable purpose. The results of investment can be demonstrated with the changes to the Compassionate Care Benefit to move from six weeks to 26 weeks to provide income assistance to

caregivers, while this benefit doesn't show on our bottom line, it is significant financial benefit for the ALS community across Canada.

## DEFERRED REVENUE

ALS Canada changed its accounting recognition method in 2014 to the Deferral Method under Generally Accepted Accounting Principles. This change in accounting policy allowed ALS Canada to set aside money in our Statement of Financial Position for future investments in research and client services.

As of December 31, 2015, the balance in deferred revenue was \$6.5 million, of which \$5 million has been classified as short term and therefore, will be paid out over fiscal 2016 for research and client services. The remaining \$1.5 million has been classified as long term and will be used in 2017 and beyond.

The funds related to the deferred revenue are currently being held in income generating secure investments. As soon as the funds have been fully committed to grants and awards, the liability will be reflected in the ALS Canada records in full and the deferred revenue balance will be reduced accordingly.

## INVESTMENTS

ALS Canada invests all funds under the guidelines of an established Investment Policy which has been approved by the Board of Directors. All investments are made with the investment policy objectives in mind and to ensure that cash requirements can be met as needed.

As of December 31, 2015, ALS Canada held \$3.5 million in cash, \$10.1 million in an income bearing savings account, \$1.0 million in government bonds and \$5.4 million in corporate bonds and GIC's.

## REVENUE AND FUNDRAISING EXPENSE

Management and the Board of Directors, carefully monitors the fundraising portfolio and the associated expenses to ensure that there are stable and sustainable revenue streams to meet the needs and goals of the organization.

Other than additional Ice Bucket Challenge funds, ALS Canada raised \$6.5 million through direct fundraising activities. 2015 represents the 15th year of the WALK for ALS events right across Canada where the net proceeds are used for investments in provincial Client Services (60%) and Research (40%). In Ontario, the WALK for

ALS raised \$1.9 million. This was a decrease from 2014 of \$180K or 8.7% from 2014. After taking into account 2014 as an anomaly due to the Ice Bucket Challenge effect, the 2015 achievement is in line with year over year growth from 2013.

An additional \$729K of provincial contributions was provided through the generosity of donors to the ALS Societies in each province through the WALK for ALS fundraisers and additional giving of \$132K directed towards research funding for a total of \$861K.

On regular fundraising, outside of the ALS Ice Bucket Challenge revenues, ALS Canada had a fundraising ratio of 28%, which is within the acceptable level for the charity sector and Canada Revenue Agency (CRA) standards.

Health Partners represented a significant funding opportunity, with \$230K provided through the generosity of employees in federal government offices and companies across Canada. This funding was used to support the ALS Canada research program and federation requirements.

## ADMINISTRATION

2015 administration expenses were \$735K, representing a ratio of 5.2% (including ALS Canada Ice Bucket Challenge Revenue).

## GOVERNANCE

ALS Canada is fortunate to have a governance model which includes a skills-based Board of Directors from across Canada. The Directors meet face to face four times a year in addition to teleconferences and other calls as required. Out of pocket expenses are reimbursed to the Directors relating to travel and accommodation, however, no compensation is provided for their generous giving of their time.

Additionally, during the year, personal donations were made by the Board as well as donations from their corporations. These donations were made to ALS Canada as well as the ALS Society in their province of residence.

2015 was a successful year for ALS Canada. In addition to the substantial increase in the grants awarded for research, it was also a year of building for the future, to meet our vision of making ALS a treatable, not terminal disease by 2024.

**STATEMENT OF FINANCIAL POSITION**

DECEMBER 31, 2015 AND 2014

	General Fund	Research Fund	Tim E. Noël Endowment Fund	2015 Total	2014 Total
<b>Assets</b>					
Current					
Cash	\$ 13,652,909	\$ -	\$ -	\$ 13,652,909	\$ 15,108,074
Short-term investments	1,516,560	-	-	1,516,560	935,961
Accounts receivable	648,729	171,676	-	820,405	1,526,934
Inter-fund transfers	(16,196,128)	16,254,380	(58,252)	-	-
Prepaid expenditures	27,482	-	-	27,482	103,491
	(350,448)	16,426,056	(58,252)	16,017,356	17,674,460
Long-term investments	3,280,090	349,664	1,358,252	4,988,006	3,997,051
Capital assets	32,434	-	-	32,434	113,020
	3,209,722	16 775, 720	1,300,000	21,037,796	21,784,531
<b>Liabilities</b>					
Current					
Accounts payable and accrued	615,869	-	-	615,869	568,616
Current portion of deferred revenue	1,201,076	3,779,615	-	4,980,691	2,244,557
Current portion of research grants payable	-	3,056,389	-	3,056,389	1,179,998
Current portion of deferred lease inducement	27,191	-	-	27,191	29,663
	1,844,136	6,836,004	-	8,680,140	4,022,834
Long-term deferred revenue	721,869	765,330	-	1,487,199	11,557,640
Long-term research grants payable	-	4,729,726	-	4,729,726	265,000
Deferred lease inducement	-	-	-	-	27,191
	2,566,005	12,331,060	-	14,897,065	15,872,665
<b>Net Assets</b>	\$ 396,071	\$ 4,444,660	\$ 1,300,000	\$ 6,140,731	\$ 5,911,866
<b>Net assets represented by Surplus</b>	\$ 396,071	\$ 4,444,660	\$ 1,300,000	\$ 6,140,731	\$ 5,911,866



**STATEMENT OF OPERATIONS**

YEARS ENDED DECEMBER 31, 2015 AND 2014

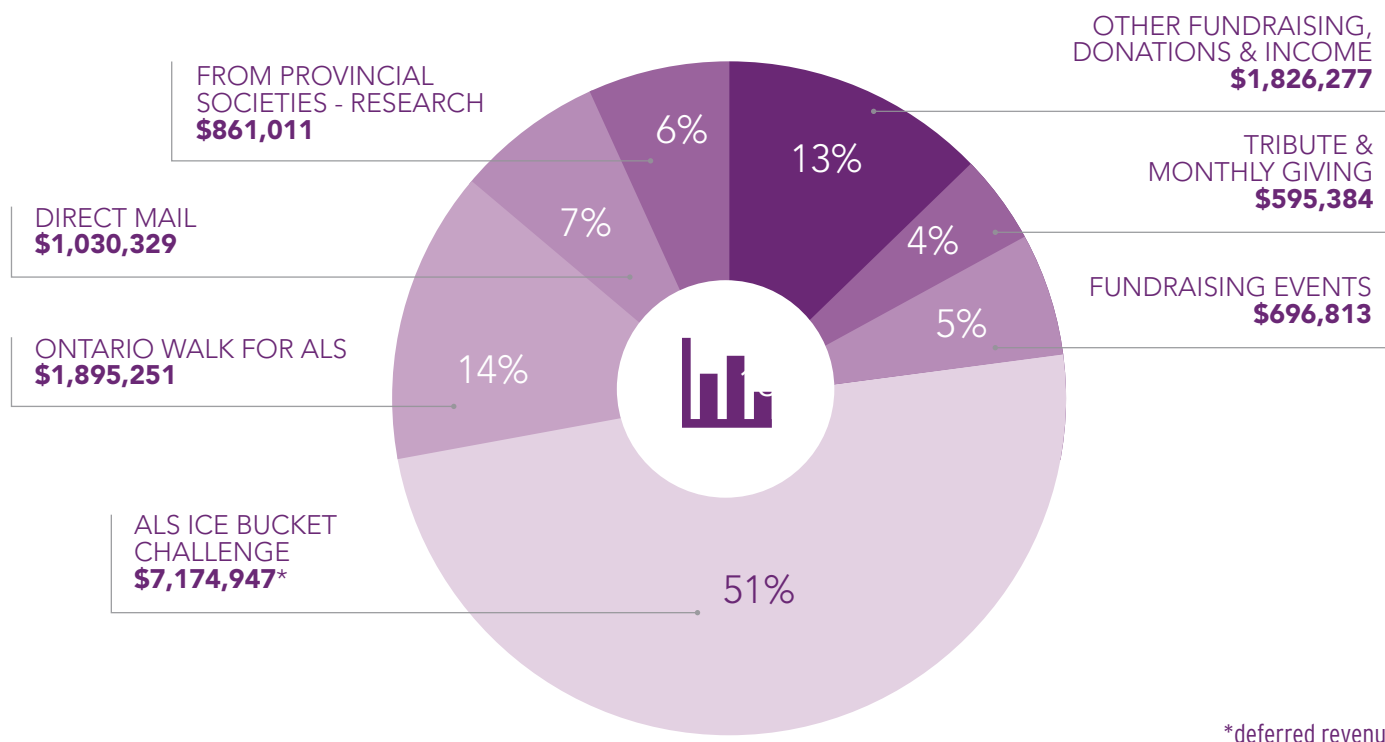
	General Fund	Research Fund	Tim E. Noël Endowment Fund	2015 Total	2014 Total
<b>Revenue</b>					
Fundraising and donations	\$ 3,675,549	\$ 9,072,355	\$ -	\$ 12,747,904	\$ 6,168,242
Direct mail campaign	1,015,258	15,071	-	1,030,329	975,804
Interest and investment income	12,955	204,613	22,416	239,984	207,715
Project grants	80,905	-	-	80,905	105,531
Unrealized gain/(loss) on investments		5,557	(24,667)	(19,110)	38,777
	4,784,667	9,297,596	(2,251)	14,080,012	7,496,069
<b>Expenditures</b>					
Research grants	-	8,057,763	-	8,057,763	1,170,000
Other research support	-	670,398	-	670,398	381,313
National federation services	85,225	-	-	85,225	228,573
Ontario client support services	1,539,708	-	-	1,539,708	1,393,944
Public awareness	440,099	-	-	440,099	433,061
Volunteer and organizational development	94,301	-	-	94,301	153,204
Project grants costs	80,905	-	-	80,905	105,531
	2,240,238	8,728,161	-	10,968,399	3,865,626
<b>Other</b>					
Fundraising	1,865,880	35,259	-	1,901,139	2,717,972
Administrative	536,549	198,450	-	734,999	553,447
Governance	123,305	123,305	-	246,610	177,302
	2,525,734	357,014	-	2,882,748	3,448,721
	4,765,972	9,085,175	-	13,851,147	7,314,347
<b>Excess/(deficiency) of revenue over expenditures</b>	\$ 18,695	\$ 212,421	\$ (2,251)	\$ 228,865	\$ 181,722

**STATEMENT OF CHANGES IN NET ASSETS**

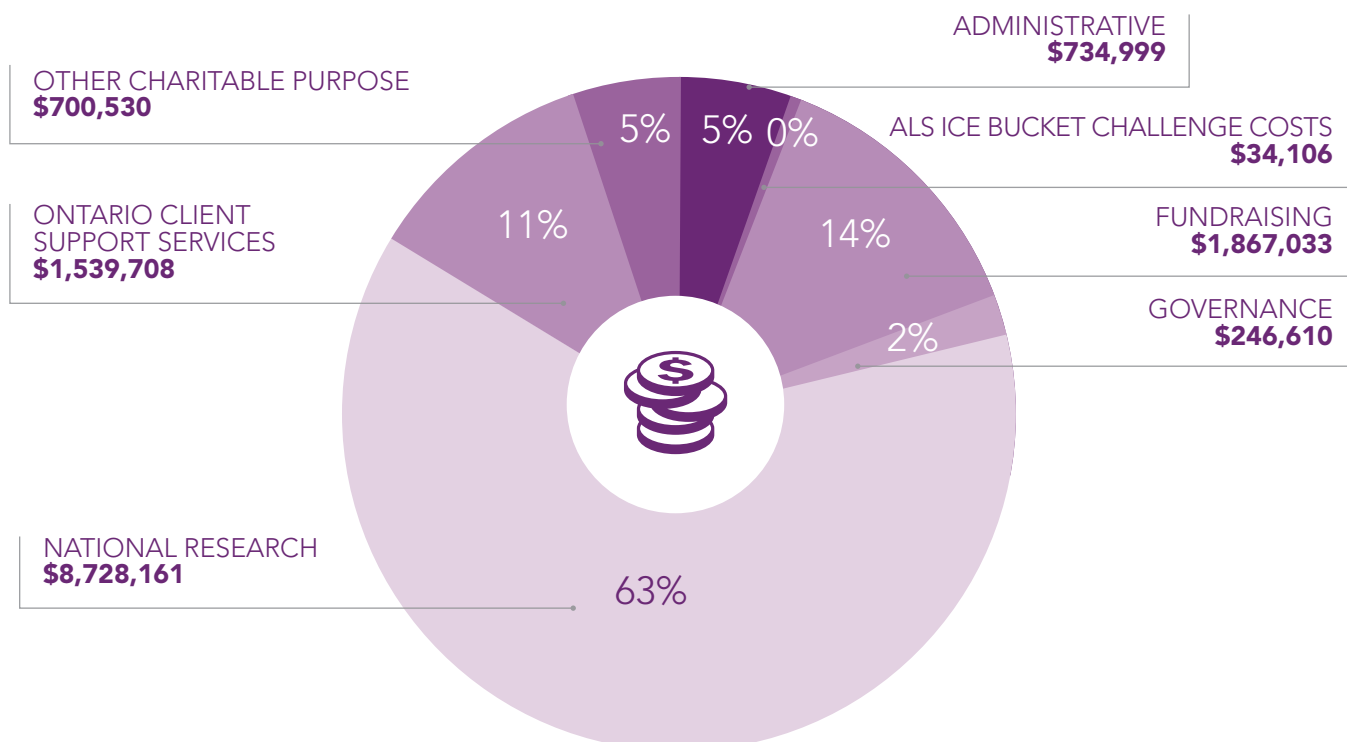
YEAR ENDED DECEMBER 31, 2015

	General Fund	Research Fund	Tim E. Noël Endowment Fund	2015 Total
Balance, beginning of year	\$ 625,022	\$ 3,986,844	\$ 1,300,000	\$ 5,911,866
Excess of revenue over expenditures/(expenditures over revenue)	18,695	212,421	(2,251)	228,865
Inter-fund transfers	-	(2,251)	2,251	-
Inter-fund transfers	\$ (247,646)	\$ 247,646		
<b>Balance, end of year</b>	\$ 396,071	\$ 4,444,660	\$ 1,300,000	\$ 6,140,731

# 2015 REVENUE



# 2015 EXPENDITURE









**ALS.CA**