



CHALLENGE ACCEPTED



ANNUAL REPORT **2014**



ALS Society of Canada
Société de la SLA du Canada

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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 2014. ALS Canada is grateful to all of our donors at all levels of support.

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AN INTRODUCTION TO ALS CANADA



We are a national organization responsible for the ALS Canada Research Program, funding peer-reviewed research grants and fostering collaboration amongst Canadian researchers, helping to nurture new ideas and build capacity.



We are one of nine partners in a federation across Canada that come together to raise funds for research through the WALK for ALS and to find ways to partner on initiatives that will benefit people living with ALS in Canada.



Like our Provincial partners, ALS Canada has a role in Ontario, where we provide services and support for people living with ALS.



We conduct direct home visits, facilitate support and bereavement groups and collaborate with community partners in palliative care, hospice, community care and occupational therapy to deliver quality programs and services to assist people and their families as they make the journey with ALS.



We also advocate federally, provincially and locally on behalf of people and their families for better government support and access within the healthcare system.



THE FACTS ABOUT ALS



ALS STANDS FOR AMYOTROPHIC LATERAL SCLEROSIS

IT IS A **NEURODEGENERATIVE DISEASE** WHERE THE NERVE CELLS THAT CONTROL YOUR MUSCLES DIE. THIS LEADS TO A **LOSS OF MOBILITY, LOSS OF SPEECH** AND EVENTUALLY IMPACTS THE **ABILITY TO BREATHE**

ALS IS A **TERMINAL DISEASE**

IN CANADA, APPROXIMATELY **2,500-3,000** PEOPLE ARE **LIVING WITH ALS**

APPROXIMATELY **1,000** PEOPLE WILL BE **DIAGNOSED** EACH YEAR, AND A SIMILAR NUMBER WILL **SUCCUMB** TO THE DISEASE

THE LIFESPAN AFTER DIAGNOSIS IS ON AVERAGE **TWO TO FIVE YEARS**

MESSAGE FROM ALS CANADA CHAIR



Thanks to a social media phenomenon, 2014 was the year ALS went 'mainstream'. The *ALS Ice Bucket Challenge* was a catalyst for thousands of people to donate to our organization and become more aware of ALS. This was a game changer for ALS Canada!

Not only did we participate in and promote the *ALS Ice Bucket Challenge*, but through the good will and unprecedented generosity of Canadians, ALS Societies across Canada were able to raise over \$17 million.

Collectively with the nine ALS Societies across Canada, \$4.4 million net was allocated towards client services and \$11.5 million net to ALS Canada's

Research Program. We announced an inaugural partnership with the Federal Government and Brain Canada, which matched Canadian's donations from the *ALS Ice Bucket Challenge* with an additional \$10 million investment into the ALS Canada Research Program.

Overall, \$26 million will be invested towards the future of ALS research and client services in Canada as a result of the *ALS Ice Bucket Challenge*.

At the same time, ALS Canada's Board was also tasked with navigating a leadership transition within the organization and recruiting a new CEO. Following a rigorous recruitment process, we were pleased to announce the appointment of Tammy Moore as Chief Executive Officer on November 10, 2014. Chosen to execute ALS Canada's strategic vision, Ms. Moore has an innate understanding of the ALS Community and an unwavering dedication to help change the future of ALS. She is the leader this organization needs to forge ahead and manage the unprecedented investments that will take place in both client services and the ALS Canada Research Program.

ALS Canada's mission is to provide support to Canadians living with ALS and invest in research to make ALS a treatable, not terminal disease. ALS Canada's Board plays an important role in

achieving this mission by defining its strategic vision, stewarding its resources, providing oversight, encouraging volunteer engagement, and ensuring accountability to the community and to the public. The Scientific Medical Advisory Council (SMAC), made up of members of the research community from across Canada, provides the Board with recommendations for the ALS Canada Research Program. We also work with the Client Service Advisory Council, which provides insight on client services and support programs to better serve the ALS Community. The Federation Council is made up of representatives from each of the nine ALS Societies across Canada.

2014 was indeed a game changer for our organization. But our challenge has not ended. Our commitment to find a treatment for this disease and to support Canadians throughout their journey with ALS continues. We extend our deepest gratitude and thanks to all of the donors and volunteers who have championed our cause and who are dedicated to changing the course of this disease.

Sincerely,

A handwritten signature in black ink, appearing to read 'Lanny McInnes'.

Lanny McInnes, Chair

ALS CANADA LEADERSHIP

Thank you to the leadership of the ALS Canada Board teams for their vision and compassion driving the organization towards meeting our vision of making ALS a treatable disease by 2024.

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Geneviève Bertrand	Josette Melanson
Dr. Heather Durham	Patrick Merz
Dr. Angela Genge	Rick Morgan
Graeme Imrie	Tracey Wallace
Cathy Martin	Jane Williamson
Lanny McInnes	Melanie York
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Dr. David Taylor, Director of Research
Tammy Moore, CEO

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ALS Canada Representatives:
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Tammy Moore, CEO

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MESSAGE FROM CEO



At ALS Canada, our mission and charitable purpose is to support Canadians living with ALS and invest in research to make ALS a treatable, not terminal disease. Together with the outstanding dedication of our donors, partners and volunteers, we are continuing to make major strides on many fronts to move our mission and strategic plan forward.

2014 was a remarkable year. The *ALS Ice Bucket Challenge* was a groundbreaking event for the ALS Community, raising public awareness of the disease and an unprecedented \$17 million from over 260,000 donors across Canada. We were prepared as an organization to wisely manage and leverage the dollars generously given and heightened public awareness to maximize the impact and carry it forward to change the future of ALS.

It set the framework to accelerate our strategic plan already in place to meet future critical support needs for clients living with ALS, make further investments in research, and step up our advocacy efforts.

This was a watershed year marked by key accomplishments and significant progress in each of the following areas:

- In Client Services, we and the Provincial ALS Societies across Canada collectively allocated \$4.4 million net through the *ALS Ice Bucket Challenge* to programs that deliver critical support to clients and families living with ALS. This significant contribution to client support services will allow each organization to sustain, enhance and expand services, support and programs to best meet the specific future needs of individual communities in each province.

- ALS Canada experienced a 8% increase in new clients, spent over \$1.4 million on client services and support, and provided direct service to over 980 people living with ALS in Ontario. We carried out a comprehensive review of our Equipment Program to consider the future sustainability of service and adapted quickly to changes in the medical device industry with innovative solutions responsive to client needs.
- In research, we directed \$11.5 million of the net raised from the *ALS Ice Bucket Challenge* to ALS Canada's Research Program to fund the best peer-reviewed Canadian research. We announced our partnership with the Federal Government and Brain Canada on November 19, which matched our investment and injected another \$10 million into research to make ALS a treatable disease. This was the first matching donation of this magnitude by the federal government to support ALS research in our history.
- We launched the Arthur J. Hudson Translational Team Grant, our largest grant competition ever, to fund teams of Canadian researchers to move ideas from the lab into the clinic and accelerate the development of new treatments for ALS. The International Peer Review Panel, comprised of seven world experts in ALS research, reviewed applications for the Arthur J. Hudson Translational Research Grants and Discovery Grants. By the end of 2014, we had cumulatively funded 62 different ALS researchers and for the first time, funded two young neurologists to specialize in ALS care and research.
- In advocacy, we adopted a targeted and strategic approach to build strong support at the federal level for changes to the Compassionate Care Benefit (CCB) that would provide caregivers with income support for 35 weeks instead of the six weeks that is offered within the current program. In the fall of 2014, we carried the weight of heightened public awareness and support for our cause into meetings with senior government officials and public servants to advocate and make it possible for changes to the CCB to be considered in the 2015 Federal Budget.
- In fundraising, the national WALK for ALS grew to include tens of thousands of participants in 90

communities across Canada and 30 communities in Ontario. Nationally, the funds raised from the WALK increased to \$4.08 million in 2014 from \$3.6 million the previous year, while in Ontario, donations increased by over 30% to \$2.075 million from \$1.53 million. Not only are the WALKS a significant fundraiser, they are a tremendous way for the ALS Community to come together, both for people currently living with ALS and to honour and remember people who have passed away.

Accepting the challenge for our organization means stewardship of the tremendous gift of support we have been given, and leveraging it for the future to help people more easily navigate the journey of ALS and change the outcome of this disease.

We want to thank the new donors who generously supported our cause this past year, and the many donors who continued to support us last year and throughout the years. We are incredibly appreciative of the dedicated volunteers who gave so tirelessly to support the needs of the community and raise the much needed funds. We are also grateful to the Board of Directors for their strategic vision and expert guidance, and our partners in Provincial ALS Societies across Canada for their valuable collaborative contributions that allow us to speak with a unified voice and purpose.

Together, we will make ALS a treatable, not terminal disease.

Sincerely,

A handwritten signature in black ink that reads "Tammy Moore". The signature is fluid and cursive, with a long, sweeping underline that extends to the left.

Tammy Moore, CEO

“ I WISH PEOPLE UNDERSTOOD THAT ALS IS A **DEBILITATING DISEASE** THAT ONLY RESULTS IN DEATH. I THINK THAT A LOT MORE PEOPLE UNDERSTAND THAT NOW, THANKS IN PART TO THE **AWARENESS** DURING THE *ALS ICE BUCKET CHALLENGE*, BUT WHAT A LOT OF PEOPLE DON'T UNDERSTAND IS THE **PROCESS** THAT PEOPLE LIVING WITH ALS GO THROUGH BETWEEN **DIAGNOSIS** AND THE **END**. UNLESS YOU HAVE BEEN INVOLVED WITH SOMEONE WITH ALS, YOU MAY NOT UNDERSTAND THE CONSTANT CHANGES AND GRADUAL **LOSS OF MOBILITY** AND **FREEDOM** THAT PEOPLE GO THROUGH WITH ALS.”

DENISE, AGE 44, LIVING WITH ALS



MEETING THE CHALLENGE WITH COMPASSIONATE CARE AND STRONG SUPPORT

In 2014, ALS Canada continued to work in close collaboration with all communities in Ontario to support the needs of Canadians living with ALS. Our team, made up of eight Regional Managers, two Coordinators, a VP of Support Services and a cohort of volunteers, provide a central point of contact for clients and ALS families. For many affected by ALS, the Client Service staff become the people client and family members can turn to and connect with to facilitate a seamless system of comprehensive care and support for daily living and are a trusted mentor to those adjusting to the stressful new realities of living with this terminal disease.

In Ontario, ALS Canada provides direct support to people living with ALS by facilitating quality care, education programs and services.

CLIENT SERVICE ACHIEVEMENTS FROM 2014

- More than **1,100 clients** registered with ALS Canada
- **2,220 requests** for the Equipment Program were processed
- The collaborative Equipment Program pilot project with Shoppers Home Health Care was **expanded** to include the Ottawa and Champlain regions
- **1,089 home visits completed** of over 2,000 offered to clients and family members
- Almost **3,080 additional contacts** with clients and families were provided through phone, email and ALS clinic visits
- **Two new support group gatherings** were initiated in the Niagara and North Bay Regions in addition to monthly meetings held in 12 other communities throughout the province

- **Two new caregiver meetings** were initiated on Saturdays to accommodate caregivers who are still working
- **Enhanced working relationship** was forged with Toronto Sunnybrook ALS Clinic resulting in Regional Managers participating in the ALS Clinic to meet with newly diagnosed clients and their families and be available to provide immediate follow up on concerns/questions of clients and families who are attending the clinic day
- Thanks to the **Green Shield Canada Foundation**, in collaboration with the London ALS Clinic Team and St. Joseph's Hospital Neurological Team, ALS Canada facilitated the first ever Northern ALS Clinic and Education Program in Thunder Bay

- Thanks to the **Pottruff Foundation** ALS Canada developed and managed a transportation fund for people living in the Durham Region
- Thanks to the **Walter J Blackburn Foundation**, computer technology was provided in the London area to enhance clients' ability to stay connected with friends, family and the community

AN OVERVIEW OF THE EQUIPMENT PROGRAM

We conducted a comprehensive review of the Equipment Program to ensure the future sustainability of this service.

- A thorough status assessment of the current Equipment Program which included meetings with key stakeholders such as clients, caregivers, healthcare professionals, ALS Canada staff and ALS Clinic Team members obtaining legal risk analysis opinion
- Information gathering on comparable charities and associations within Canada, in the United States and internationally to provide benchmarking data
- Development of Equipment Program models, discussion and modification of models to be taken out for further consultation
- Participated in Queen's Park Hill Day to advocate for the expansion of equipment funded by ADP and enhancing approved time for new products to enable clients with ALS to have access to current and leading edge equipment
- Completed client experience survey regarding the Equipment Program revealed 97% of returned surveys rated the equipment program as being of value to them



\$1.4 MILLION WAS SPENT ON CLIENT SERVICES SUPPORTING PEOPLE LIVING WITH ALS IN ONTARIO



DIRECT SERVICE WAS PROVIDED TO OVER 984 CLIENTS LIVING THROUGHOUT THE PROVINCE



AN 8% INCREASE IN NEW CLIENT REGISTRATIONS RESULTING IN AN OVERALL INCREASE OF 3% IN ALS CANADA CLIENT CASELOAD

A TARGETED APPROACH LEADS TO ADVOCACY GAINS



From left to right: **Brian Parsons**, CCB Advocate, **Rick Morgan**, ALS Canada Board Member, **Dr. Heather Durham**, ALS Canada Board Member, **Tammy Moore**, CEO, ALS Canada, **Patrick Merz**, ALS Canada Board Member, **Dr. David Taylor**, Director of Research, ALS Canada

Advocacy for ALS Canada means stepping up and speaking up to lobby and influence the federal government to make meaningful changes, which will ease the economic burden for families living with ALS and provide a stable, sustainable source of funding for research.

ALS is sometimes called the bankruptcy disease because the needs are so much more extensive and expensive than for other illnesses. The economic burden for a Canadian family is between \$150,000 and \$250,000 in direct and indirect costs over the short window of the diagnosed person's life. The expenses borne by ALS clients and their families include direct costs, such as home renovations and mobility equipment, and substantial indirect costs, in terms of lost income. While ALS Canada provides

much needed assistance through equipment and care support programs, the reality is that two-thirds of direct expenses on average are paid for out-of-pocket by Canadian families.

Better support for ALS families is urgently needed. Under the current Employment

caregiving to a terminally ill family member. Additionally there is a two week waiting period, so for the caregiver can receive a maximum of \$3,144 for eight weeks. To access the benefit, a doctor's note must be provided stating death is imminent within six months. Six weeks' coverage is too short to meet the needs of caregiving for

“ **ADVOCATING FOR ALS IS ABOUT USING OUR VOICE TO INFLUENCE GOVERNMENT. IT'S ABOUT TELLING THEM WHAT THEY NEED TO DO AND GIVING THEM GOOD REASONS TO DO IT.**”

DR. DAVID TAYLOR, DIRECTOR OF RESEARCH, ALS CANADA

Insurance Program, the Compassionate Care Benefit provides up to six weeks of benefit coverage (maximum of \$524 per week) for a person to take leave from work to provide

a loved one with ALS and is often not accessed as the caregiver will have already lost their job to stay home and provide care.

“ACCEPTING THE CHALLENGE OF ADVOCACY MEANS WE NOW CARRY THE WEIGHT OF **3,000 PEOPLE** LIVING WITH ALS AND MORE THAN **260,000 VOICES** SUPPORTING THE ALS COMMUNITY IN CANADA. IT’S UP TO US TO LEVERAGE THOSE VOICES TO **CARRY THE MOMENTUM** FORWARD AND TRANSLATE THE **CHANGES** WE ARE ASKING FOR INTO **REALITY.**”

TAMMY MOORE, CEO, ALS CANADA

On behalf of the ALS Community, ALS Canada is advocating for two key issues at the federal level. We are asking the government to enhance the Compassionate Care Benefit, to provide eligibility upon diagnosis of a terminal, rapidly progressive, neurodegenerative disease and at the point of application the physician has determined the transition to palliative and/or supportive care within a two year period is imminent. We are also requesting the benefit be extended from six weeks to 35 weeks to provide a longer period more aligned to the palliative care needs.

If implemented, the changes would have a significant impact to ease the financial burden of the most financially vulnerable, working age, ALS families. It is anticipated this change would provide between \$3.5 to \$7 million annually in direct income support to Canadian families living with ALS.

We continue to advocate the government to match dollar for dollar the \$1.5 million that ALS Canada has historically invested annually in research towards making ALS a treatable, not terminal disease. We remind government that these funds are provided through the generosity of Canadians who believe in this cause and the work that is being done.

PROGRESS ACHIEVED THROUGH THE YEAR

We stepped up our advocacy efforts in 2014 with a redesigned, targeted and strategic approach that accelerated our progress towards achieving changes to the Compassionate Care Benefit and matching funding for ALS research. Our aim was to build awareness, political support, positive

momentum and ultimately to gain champions at the highest level of government leading to implementation of our asks.

Rather than doing a large scale annual ALS Hill Day, a few specific advocates - CEO, Tammy Moore, Director of Research, Dr. David Taylor and Brian Parsons, who is living with ALS and has extensive experience working on Parliament

“ACCEPTING THE CHALLENGE OF ADVOCACY MEANS **STEPPING UP** AND SHINING A LIGHT ON THE OBSTACLES THAT PREVENT US FROM FINDING A TREATMENT AND ULTIMATELY A CURE FOR THIS ILLNESS. IT MEANS **EXPOSING THE ISSUES** THAT IMPOSE **ADDITIONAL BUT AVOIDABLE BURDENS** ON THOSE WITH ALS AND THEIR FAMILY MEMBERS. **ACCEPTING THE CHALLENGE** MEANS TO **NOT SILENTLY ACQUIESCE** TO OUR DEMISE.”

BRIAN PARSONS, A CLIENT WITH ALS AND ADVOCATE FOR CHANGES TO THE COMPASSIONATE CARE BENEFIT AND SUSTAINABLE GOVERNMENT FUNDING FOR RESEARCH

Hill - met over several months with dozens of key MPs and political staff, in over 50 meetings, who had direct influence over the planning and implementation of policies we needed to change.

When over 260,000 Canadians demonstrated their support last August by accepting the *ALS Ice Bucket Challenge* and donating, this raised public awareness of ALS and our cause tremendously and elevated the status of ALS Canada on Parliament Hill. People within government also accepted the *ALS Ice Bucket Challenge* and that gave us a different way of talking to them about making a difference by acting on these key issues now. After diagnosis, people with ALS are told they have an average

of two to five years to live, so there is no time to wait.

We seized the moment and accepted the challenge by carrying those many voices forward into meetings with the Minister of Health, the Department of Employment and Social Development and senior public servants responsible for the Compassionate Care Benefit, as well as senior officials in the Prime Minister’s Office and Finance Department. We took all the necessary steps to build political support at the highest levels and make it possible for changes to the Compassionate Care Benefit to become a reality for families living with ALS.

On November 19, ALS Canada announced on Parliament Hill that ALS Societies across Canada dedicated \$11.5 million net towards research

from funds raised through the *ALS Ice Bucket Challenge* and an additional \$10 million in matching funds through a partnership with Brain Canada and the federal government. This was the first matching donation of this magnitude by the federal government to support ALS research. While this large contribution will have an immediate transformative impact in accelerating research towards a treatment, it is still not a secure and sustainable source of funding.

By the end of 2014, the advocacy team saw very positive momentum and political support building for consideration of changes to the Compassionate Care Benefit in time for the 2015 Federal Budget.

VISION: BY 2024 ALS WILL BE A TREATABLE DISEASE



DR. DAVID TAYLOR, PHD,
DIRECTOR OF RESEARCH

 @ALSCANRESEARCH

Your donations over more than a decade have allowed us to set the table for the breakthroughs we all expect in the foreseeable future. These investments have helped make Canadian ALS research an important contributor in the global effort toward understanding the disease and finding ways to slow it down. In 2013/2014, your generosity has provided funding for novel ideas, prepared the future generation of ALS researchers and clinicians to carry the torch into the future and maintained the momentum of key ALS projects.

As we look back on 2014, the number of differences in our Research Program is staggering. The Arthur J. Hudson Translational Team Grant was the largest financial commitment in our program's history. It was also ALS Canada's strongest commitment to nurturing new therapies for ALS and utilizing the research infrastructure built in Canada to its maximum efficiency for the benefit of Canadians living with ALS. The applications were reviewed by ALS Canada's first ever International Peer Review Panel (IPRP). The IPRP is an important

component for ALS Canada to continue funding the best research to move the field forward. Consisting of seven world experts on ALS, with varying areas of expertise across the basic/clinical research spectrum, the IPRP maximizes the efficacy of donor funds.

Our grant program continued to support crucial projects and individuals in 2014 as we work steadily towards meeting the ALS Canada Research Program strategic goal:

TO DEVELOP AT LEAST ONE NOVEL THERAPEUTIC STRATEGY, THROUGH A NATIONAL NETWORK, TO SLOW THE PROGRESSION OF ALS BY 2017.

APRIL / MAY

We awarded a Doctoral Research Award and Postdoctoral Fellowship - grants that provide salary support for top ranked junior researchers to pursue projects focused on ALS.

JUNE

ALS Canada invested in four ALS Canada Bridge Grants. Designed to support continued momentum of the top ALS projects in the country, these grants are critical to maintaining the excellence of the Canadian ALS research community in its contribution to the global effort to solve ALS.

DECEMBER

We partnered with Brain Canada to support five Discovery Grants; the most we have ever given in one year. Designed to provide seed funding to the top 'outside-the-box' ideas for understanding and treating ALS, this work explores novel ideas and techniques that would likely have difficulty receiving funding from traditional sources.

As another first in the ALS Canada Research Program, we awarded two Bernice Ramsay Clinical Research Fellowships - awards which provide training for young neurologists in ALS clinical care and research. It is one example where ALS Canada can simultaneously enhance the future care that Canadians living with ALS will receive, while strengthening the community's ability to perform clinical research and clinical trial readiness.

ADVANCEMENTS IN ALS

As for the state of ALS research, we have made progress.

In late 2011, one of the biggest breakthroughs in ALS research history came when a gene called C9ORF72 (colloquially referred to as 'C9'), when carrying a unique type of mutation, was discovered to cause more cases of familial ALS than any other, as well as to have an impact on a percentage of sporadic cases. What followed was a rapid scrambling of researchers to learn about this new gene, what its normal functions were and how it fit with the other major players in ALS pathology, namely SOD1, TDP-43 and FUS. If 2012 was about how to study C9 and 2013 was about gaining the first look at what it does, 2014 has been about interpreting that understanding into ways to target ALS for a new generation of therapies. Previously, most therapeutics that reached clinical trial were derived from studies using models of mutant SOD1-mediated disease only. As new therapies are developed, they will be done so with all of the known causes and affected mechanisms in mind and will be tested in new models including human motor neurons and glia derived from adult skin cells; something that is becoming more ubiquitously used and may more effectively represent the end result in a human clinical trial. The past few big trials, though resulting in failure to slow

disease progression, have been significant in the information they provided on how to better approach future studies.

CHALLENGE ACCEPTED

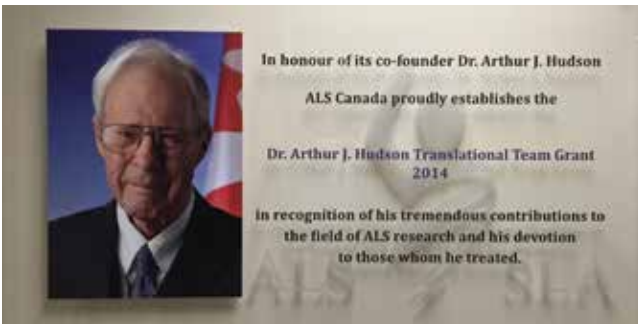
We stand poised to increase our investment in

ALS research over the coming years, thanks to your outpouring of support through the *ALS Ice Bucket Challenge*. Our researchers accept the challenge and are ready with visionary projects they couldn't previously consider and our Research Program is ready with infrastructure

built to take ideas efficiently from the concept stage through to clinical trials. We continue to push forward in making ALS a treatable disease by 2024.

PURELY CANADIAN COLLABORATIONS

THE 2014 ALS CANADA RESEARCH FORUM



Arthur J. Hudson Translational Team Grant Award

2014 marked the 10th anniversary of the ALS Canada Research Forum: a collective platform that brings the Canadian research community together to exchange ideas in a unified manner,

of Dr. Hudson's contribution to the field of ALS research, we also unveiled the Arthur J. Hudson Translational Team Grant at the Forum. This is the largest investment ever

to understand ALS and to find new avenues to treat the disease. We were proud to give the inaugural lifetime achievement awards to two Canadian ALS research legends, the late co-founder of ALS Canada, Dr. Arthur J. Hudson and the father of Canadian ALS clinical trials, Dr. Andrew Eisen. In honour

made in ALS Canada's history and is focused on a collaborative, team approach to accelerate discovery and translation of ALS treatments from bench to bedside.

In attendance was the entire, world-class Canadian ALS research community from across the country. It is because of your support, we are able to continue to bring researchers together through the ALS Canada Research Forum.

Together, we collaborate and exchange information with the vision to make ALS a treatable, not terminal disease.

100% INCREASE IN APPLICATIONS FROM 9 TO 18 APPLICATIONS FOR DISCOVERY GRANTS VS. 2013

THE INTERNATIONAL PEER REVIEW PANEL COMPRISED OF ALS EXPERTS REVIEWED ALS CANADA **RESEARCH GRANTS**



INITIATED A TRANSLATIONAL APPROACH TO FUNDING RESEARCH TO ACCELERATE THERAPEUTIC DEVELOPMENT



WE INVESTED **\$1.55 MILLION** IN **ALS RESEARCH**

WE LAUNCHED THE LARGEST GRANT COMPETITION, THE **ARTHUR J. HUDSON TRANSLATIONAL TEAM GRANT**



62 SINCE 2006 WE'VE **FUNDED 62** DIFFERENT ALS **RESEARCHERS**

HERE ARE THE PROJECTS YOU HELPED FUND IN 2014.



ALS CANADA BRIDGE GRANTS

Our Bridge Grants offer short-term funding of one to two years (\$100,000 per recipient) to keep the momentum of research projects when they have not been able to secure full government funding.

DR. NEIL CASHMAN

University of British Columbia

Pathobiological mechanisms of misfolded wild-type Cu/Zn superoxide dismutase: A common pathway in amyotrophic lateral sclerosis

DR. STEVEN PLOTKIN

University of British Columbia

Computation and theory to predict structures and mechanisms for protein misfolding in degenerative disease

DR. MICHAEL STRONG

University of Western Ontario

Characterization of RGNEF-a novel RNA binding protein that forms pathological aggregates in ALS

DR. JASNA KRIZ

Université Laval

Glia-neuron crosstalk in early amyotrophic lateral sclerosis pathogenesis



ALS CANADA – BRAIN CANADA DISCOVERY GRANTS

Five recipients received the ALS Canada - Brain Canada Discovery Grants. Each grant provides funding for one year (\$100,000 per recipient) to build a foundation of data for novel, 'outside-the-box' ideas in ALS research.

DR. CHARLES KRIEGER

Simon Fraser University

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

DR. JANICE ROBERTSON

University of Toronto

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

DR. MELANIE WOODIN

University of Toronto

Synaptic inhibition in the motor cortex of an ALS mouse model

DR. HEATHER DURHAM

Montreal Neurological Institute

Epigenetic mechanisms underlying dendritic atrophy in ALS

DR. ALEX PARKER

Université de Montréal

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



BERNICE RAMSAY CLINICAL RESEARCH FELLOWSHIP

The Clinical Research Fellowship (funding up to \$200,000) provides two years of funding for a young neurologist to receive specialized training in ALS care and research. It is designed to increase the number of ALS focused clinicians across Canada and to potentially build clinical research infrastructure in underserved regions of the country.

DR. AMANDA FIANDER

University of Calgary

A Phase II randomized placebo controlled trial testing Withania somnifera in volunteers with amyotrophic lateral sclerosis (ALS)

DR. MARVIN CHUM

Western University/
London Health Sciences Centre

Palliative care and respiratory support of patients with ALS



TIM E. NOËL POSTDOCTORAL FELLOWSHIP

The Tim E. Noël Postdoctoral Fellowship provides \$165,000 spread over three years for salary of a promising postdoctoral researcher, nurturing bright young minds into focusing on ALS as a potential career.

DR. CLAIRE LEBLOND

Montreal Neurological Institute,
McGill University

Testing for somatic mutation in sporadic amyotrophic lateral sclerosis



ALS CANADA DOCTORAL RESEARCH AWARD

This award provides \$105,000 spread over three years, for salary of a promising PhD student who will work on ALS.

ALEXANDRA LISSOUBA TATARINOFF

Université de Montréal

Comparison of gene expression patterns between different genetic models of amyotrophic lateral sclerosis



ARTHUR J. HUDSON TRANSLATIONAL TEAM GRANT (2015)

DR. LAWRENCE KORNGUT &

DR. LORNE ZINMAN

University of Calgary & Sunnybrook Health Sciences Centre

A randomized controlled trial of pimozone in subjects with ALS

DONOR SUPPORT RAISES THE WALK FOR ALS TO NEW HEIGHTS



“ THE WALK FOR ALS IS MORE THAN A FUNDRAISER. IT BRINGS PEOPLE **TOGETHER** IN SUPPORT OF EACH OTHER WHO ARE GOING THROUGH THE **JOURNEY** OF THIS DEVASTATING DISEASE.”

ENZO RAPONI, DIRECTOR,
NATIONAL WALK FOR ALS AND
PLANNED GIVING, ALS CANADA



The annual WALK for ALS is our largest fundraiser, driven by the strong participation of people living with ALS and their families, and tens of thousands of their supporters in 30 communities in Ontario and 90 communities across Canada in 2014. The WALKS bring people together to raise awareness and are made possible through the dedicated efforts of volunteer organizers in those communities.

For each and every one of the people involved in WALKS throughout Ontario and across Canada last year, their active participation was a powerful way of stepping up to the challenge of ALS and facing it head on. “The WALK is an amazing show of support for the families living with ALS. People come out either in memory or in honour of the person who has ALS,” says Lianne Johnston, South East and Champlain Regional Manager for ALS Canada.

The WALKS give clients living with ALS and their families vital and energizing morale and emotional support. “The WALK for ALS is a community event to bring people together who are facing the challenges of ALS and to know they are not alone in the journey,” says Charlene Spector, South West, Grey-Bruce and Niagara Regional Manager for ALS Canada.

ALS Canada needs the WALK for ALS to deliver on our charitable purpose. The WALKS have a

huge impact with 40% of the proceeds going directly to the ALS Canada Research Program and 60% funding a wide range of support services, equipment and educational programs to help ALS clients and their families navigate the journey through this disease.

“By coming to the WALK for ALS you are supporting the ALS Community not only by funding research, but you’re also funding client services. If someone needs a wheelchair or hospital bed, that’s where your dollars are going. It makes me really happy to see the WALKS grow,” says Michelle Roebuck, Wingham WALK coordinator.



WALK REVENUES GROW, NUMBER OF TEAMS DOUBLES

Growth was the hallmark of the WALK for ALS nationally and in Ontario in 2014. A total of \$4.08 million was raised as 90 communities across Canada WALKED for ALS, a substantial increase from \$3.6 million in 86 communities in 2013. Nationally, the number of teams that

participated in the WALK more than doubled to 1,582 from 765 the previous year.

In Ontario, a total of \$2.075 million was raised through WALKS in 30 communities, an increase of over 30% from \$1.53 million in 28 communities in 2013. The number of teams that stepped up for the WALK rose to 863 from 532 the previous year.

The promotion of friendly team competitions in communities to step up the dollars raised through WALKS contributed to the impressive growth in the number of teams and revenues raised during the year. Overall participation also increased as the ALS Community came together at each of these events both to support people living with ALS, and remember people who have passed away with butterfly ceremonies and memorial walls.

Accepting the challenge in fundraising, we will be stepping up from 30 to 32 WALKS in Ontario and have set a target of \$2.25 million for 2015. In achieving this goal, we would be increasing the core funds raised for client services and investment in research by nearly 50% in two years. Nationally, we will be stepping up from 90 to 93 WALKS and have set a target of \$4.3 million for 2015.

ICE, WATER AND A BUCKET TRANSFORMS ALS

In the summer of 2014, the *ALS Ice Bucket Challenge* owned headlines all over the world. Documented in over 4.7 million social media videos worldwide, we were both the observer and participant in the phenomenon that captured the hearts, spirit and curiosity of millions of Canadians. The idea of putting ice in a bucket, dumping it over your head and calling out neighbours, friends, family, colleagues and even strangers to donate to support ALS, generated **\$17 MILLION** to our organization - an unbelievable and unimaginable achievement that has transformed ALS. A disease that for the past 75 years or more has been invisible to so many Canadians had become a part of everyday conversations in unabashed transparency, amplified on a magnified social platform that brought everyone from every part of the world together. This was the *ALS Ice Bucket Challenge*.

HOW IT STARTED FOR ALS CANADA

As a team, we first heard about the *ALS Ice Bucket Challenge* at the end of July. Early August in 2014, we received emails and calls from personal friends asking if we had heard about this thing called the *ALS Ice Bucket Challenge*. At the time, it piqued our interest, but we never could have predicted the implications of what this simple idea would do for all of us in the ALS Community.

This changed the week of August 4, when hockey icon, Sidney Crosby, posted his *ALS Ice Bucket Challenge* video. That's when our phone started ringing. Not from the media, but from members within the ALS Community. Everyone shared an enthusiasm and unparalleled excitement to get involved, to use the *ALS Ice Bucket Challenge* as an opportunity to fundraise and asked for our help in setting up personal pages to share with their friends and family.

In the week from August 4-10, we had 39 donors, who raised \$1,800 towards the Challenge. It grew from there and has not stopped even up to present day.

THE TRAJECTORY OF THE ALS ICE BUCKET CHALLENGE

The *ALS Ice Bucket Challenge* was embraced and championed by celebrities, sports athletes, CEOs, political leaders to the everyday citizen. For a moment in time, we were intricately integrated, harnessing the power of empathy, compassion and conviction to transform the reality of this devastating disease.

On Thursday August 12, Canadian hockey player Paul Bissonette upped the ante and took the *ALS Ice Bucket Challenge* to a mountain top. This caught the attention of media and from this point on for the next month every single media outlet across Canada was either in our office or on the other end of our phone. CBC, CTV, Global News, The Globe and Mail, The National Post, The Toronto Star, Macleans Magazine - hundreds of media requests with an unquenchable demand to stream updated content 24 hours a day.

We went live with the *ALS Ice Bucket Challenge* website on August 14. Traffic to the site hit 33,448 users, donations increased to over \$122,000 and our donor count went up to 2,296. The following week it broke records with the

“ IN LESS THAN TWO WEEKS, THE [ALS] ICE BUCKET CHALLENGE HAS **TRANSCENDED** SPORTS AND SPREAD INTO **POLITICS** AND **POP CULTURE...**”

THESTAR.COM, AUGUST 13, 2014

help of philanthropist and entrepreneur W. Brett Wilson. Through his influence, Canadians generously gave over \$4 million in one week. This resulted in the collapse of als.ca trying to accommodate the 105,000 users per day visiting the site. The Challenge continued to gain momentum with Randy Carlyle, former Maple Leafs Coach and ALS Canada WALK for ALS spokesperson, posting his video under the unwavering microscope of media attention.

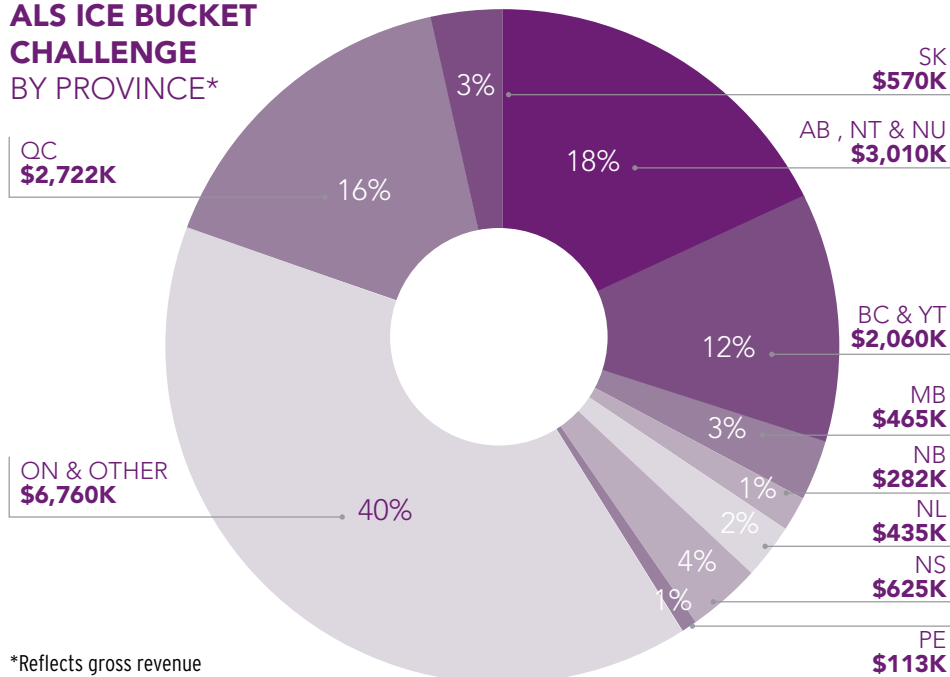
By December 31, 2014, over \$17 million had been brought into the ALS Societies across Canada.

OVER 260,000 Canadians donated to help people living with ALS and millions raised their voice to champion the cause.

LOOKING TO THE FUTURE: WHERE THE DOLLARS WILL GO

What happens now? The year ended with an official announcement made by our organization that we had formed a partnership with the federal government and Brain Canada to match \$10 million from the funds given

ALS ICE BUCKET CHALLENGE BY PROVINCE*



*Reflects gross revenue

through the *ALS Ice Bucket Challenge* to be directed to ALS research; a total investment of \$20 million to be invested to find a treatment for ALS. The remaining dollars, \$4.4 million net were distributed across Canada to the ALS Societies to fund client support services to help Canadians living with ALS navigate their journey with this disease.

In the latter end of 2014, ALS Canada announced an investment of \$500,000 to five top ALS researchers across Canada, to fund novel research projects in efforts to accelerate finding a treatment for ALS. We also announced in January 2015, a \$500,000 investment to world-class researchers in Calgary and Toronto to fund a clinical trial and biomarker study for the drug pimizide. These investments would not have been possible without the support garnered through the *ALS Ice Bucket Challenge*.

The *ALS Ice Bucket Challenge* has now been ingrained into humanity's societal conscious on a global scale. On August 6, 2015, the International ALS Community is coming together to celebrate and honour the anniversary of the *ALS Ice Bucket Challenge*. There is no turning back. This is indelible. ALS will be a treatable disease in the future.

“ I THINK THE MAIN THING (ABOUT THE *ALS ICE BUCKET CHALLENGE*) IS THAT THE MONEY IS **USEFUL** BUT WHAT STRIKES ME IS THAT SO MANY PEOPLE ARE **TOTALLY AWARE** OF IT. SINCE (THE *ALS ICE BUCKET CHALLENGE*) NO ONE HAS ASKED ME - WHAT IS ALS?”

ROSALIND SLATER

WHAT THE *ALS ICE BUCKET CHALLENGE* MEANT TO THE COMMUNITY

During the *ALS Ice Bucket Challenge* we received many calls from families affected with ALS. Families who openly shared their story with media and who worked along with us to continue to raise awareness for what this disease is and does to a family. From the community their words reverberated with grace, gratefulness and solidarity of being thankful for this public display of support.



“ FOR ME [THE *ALS ICE BUCKET CHALLENGE*] MEANT THAT FOR A MOMENT, WE **WEREN'T** SUFFERING **ALONE**. IT ALSO MEANT THAT MAYBE ONE DAY SOMEONE WOULDN'T HAVE TO GO THROUGH WHAT OUR FAMILY WAS. WATCHING PEOPLE DUMP A BUCKET OF ICE ON THEIR HEADS, WHILE IT SEEMED TRIVIAL TO SOME, MEANT **EVERYTHING** TO US. EVERY DAY I WOULD GO VISIT MY DAD AT THE HOSPITAL, AND I WOULD PULL UP DIFFERENT VIDEOS OF OUR FRIENDS, AND STRANGERS, AND CELEBRITIES DOING THE *ALS ICE BUCKET CHALLENGE*. WHILE HE LAY THERE IN BED, UNABLE TO MOVE, TALK, EAT, HE WOULD WATCH THE VIDEOS AND WOULD **SMILE** FROM WITHIN - SOMETHING HE COULDN'T DO VOLUNTARILY. SO PERSONALLY, TO ME, THE *ALS ICE BUCKET CHALLENGE* **MEANT EVERYTHING**.”

VANESSA BURNEY

“ WHEN MY FATHER GOT DIAGNOSED WITH ALS, I WAS 14 YEARS OLD IN GRADE 8. I DIDN'T KNOW WHAT ALS WAS, OR WHAT IT MEANT. ONE DAY, I GOOGLED IT DURING COMPUTER CLASS IN SCHOOL. READING HOW MY DAD MAY ONLY **LIVE TWO TO FIVE YEARS** WAS **DEVASTATING**, AND HOW HE WASN'T GOING TO BE THERE FOR ME TO DANCE WITH AT MY GRAD OR TEACH ME TO DRIVE. NO MORE DAD. WHEN I FIRST READ AND WATCHED VIDEOS ON THE *ALS ICE BUCKET CHALLENGE*, I WAS **IN SHOCK**. BUT I THOUGHT THAT MAYBE A CHILD WON'T HAVE TO GOOGLE ALS TO FIND OUT WHAT IT IS THAT THEIR LOVED ONE IS SLOWLY DYING FROM.”

MIKAELA OATES

“ I THINK HE WAS THE **HAPPIEST** I'D SEEN HIM IN SO VERY LONG BECAUSE HE WAS PART OF SOMETHING VERY **INTERESTING**.”

ELIZABETH ROBERTSON
SPEAKING ABOUT HER HUSBAND TIM,
LIVING WITH ALS

“ OUR FAMILY HAS BEEN DEEPLY AFFECTED BY ALS. IN 1997, MY 44 YEAR OLD HUSBAND STARTED HAVING SYMPTOMS IN JUNE/JULY. HE DIED IN NOVEMBER OF THAT SAME YEAR. IN JULY 2011, I GOT A CALL FROM MY SON-IN-LAW TO SAY THAT MY OLDEST DAUGHTER HAD BEEN DIAGNOSED WITH ALS. HER SYMPTOMS STARTED IN THE EARLY SPRING AND SHE PASSED AWAY SEPTEMBER 30 THAT SAME YEAR. SHE WAS 29 YEARS OLD. THEN THE **UNTHINKABLE** HAPPENED. OUR YOUNGER DAUGHTER STARTED HAVING SYMPTOMS IN JULY 2013. SHE PASSED AWAY MARCH 2014. SHE WAS 28 YEARS OLD. MY WHOLE WORLD HAS BEEN **SHATTERED** BY THIS DISEASE. A FEW MONTHS AFTER LOSING OUR YOUNGER DAUGHTER, I HEARD ABOUT THE *ALS ICE BUCKET CHALLENGE*. IT MADE ME FEEL BETTER THAT ALL OF THIS MONEY WAS BEING RAISED FOR ALS. IT'S TOO LATE FOR MY FAMILY, BUT I HOPE THEY FIND A CURE FOR THIS HORRIBLE **DEVASTATING** DISEASE.”

JOAN AIRHART

“ WHEN I WAS TELLING PEOPLE ABOUT MY DIAGNOSIS IT WAS EASIER IN THE SENSE OF I DIDN'T HAVE TO GO INTO THE LONGWINDED (DESCRIPTION) OF WHAT (ALS) IS (AND) WHAT WAS GOING TO HAPPEN. IN A WAY IT WAS A LITTLE **BIT OF RELIEF**. SEEING THE **IMPACT** OTHER PEOPLE HAD DOING THE *ALS ICE BUCKET CHALLENGE* AND JUST COMING FORWARD WITH THEIR DIAGNOSIS, IT WAS **INSPIRING**. IT **ENCOURAGED** ME TO GET IT OUT THERE.”

REBECCA SMITH



PULLING A PLANE, HITTING A BALL AND RIDING A BIKE

ALS Canada hosts a range of fun activities at various times throughout the year to support people living with ALS and their families in Ontario, and fund research to make ALS a treatable, not terminal disease.

“ ALS CANADA EVENTS, AND THE WALK FOR ALS, ARE A WAY FOR PEOPLE TO **COME TOGETHER** AND FEEL **INSPIRED** TO MAKE A **DIFFERENCE**. BY PARTICIPATING, PEOPLE ARE **ACCEPTING THE CHALLENGE** AND CHOOSING TO BE PART OF THE **ALS COMMUNITY**.”

KATHRYN RODGERS, EVENTS MANAGER, ALS CANADA



the Jim Hunter ALS CYCLE FOR A CURE



The Bombardier Plane Pull for ALS Canada is a unique, exciting event in which teams of ten people compete to pull a 37,000 lb plane 100 metres down a runway in the shortest period of time. Over \$124,000 was raised in 2014, an increase of more than \$33,000 from the previous year, through an amazing show of strength by both competitive teams and family teams.

Since 2001, the ALS Canada Golf Classic, with the help of over 1,500 golfers has raised over \$2 million to support the ALS Community. In 2014, this event was held at the prestigious Angus Glen Golf Course and tallied \$40,000 on the scorecard.

The Jim Hunter ALS Cycle for a Cure raised over \$180,000 last year to fund critical research projects to find an effective treatment for ALS. This remarkable event is a result of the commitment and resilience of Jim Hunter, who is living with ALS, and is held in partnership with the Tanz Centre for Research in Neurodegenerative Diseases, University of Toronto. Over 180 cyclists, including 46 new participants, rode either a 20 km or 70 km route to support ALS research.

2014 MANAGEMENT DISCUSSION & ANALYSIS

ALS ICE BUCKET CHALLENGE

2014 was the most significant financial year in the 38 year history of ALS Canada. Thanks to the profound generosity of Canadians, more than \$17 million was raised across Canada through the *ALS Ice Bucket Challenge*. Previously normal aggregate annual revenues were approximately \$14 million for the ten ALS Societies across Canada, with approximately half of that represented by ALS Canada.

For the *ALS Ice Bucket Challenge*, donations were tracked back to the province from which the donor was identified. Funds were attributed to the ALS Society in that province for their Board to decide on the proportion they would direct to the ALS Canada National Research Program and what would be retained in their province. The remaining amount was to be utilized by that Society to support client services in their province and the areas of greatest need.

Through their independent decisions and the generosity of the ALS Societies across Canada, more than \$11.5 million of the \$17 million was directed to research, which enabled ALS Canada to secure matched funds of \$10 million from a new partnership with Brain Canada and their public-private partnership with the Government of Canada.

The *ALS Ice Bucket Challenge* also made possible new investment in Client Services throughout Canada. The ALS Societies in Canada have set aside a total of \$4.4 million of the *ALS Ice Bucket Challenge* net proceeds to support Canadians living with ALS. As the organization providing Client Support in Ontario, ALS Canada set aside almost \$1.9 million in 2014 for future projects to better serve clients and their families in Ontario. ALS Canada's stewardship of these funds has begun with identifying impactful, compassionate programs with long-term sustainability.

DEFERRED REVENUE

In order to ensure transparent stewardship of these funds in the future, ALS Canada changed its accounting treatment for designated donations to a Deferral Method. This means that monies held to fund future projects will be recognized as revenue in the same year they are committed.

ALS Ice Bucket Challenge expenses at \$924,146, predominantly credit card and donation receipt processing, represented of 6.56% of the \$14.1 million

in *ALS Ice Bucket Challenge* revenue brought in directly by ALS Canada. Using the Deferral method of accounting procedure, dollar for dollar revenue was matched to this expense resulting in reporting of a 100% fundraising expense for the *ALS Ice Bucket Challenge* in 2014. This will be offset in future years as the Deferred Revenue will not have an associated fundraising expense as it is recognized each year.

INVESTMENTS

In keeping with ALS Canada's Investment Policy objectives "...to balance the need to meet cash flow requirements and, at the same time, to preserve and enhance capital for future obligations..." at December 31, 2014 ALS Canada held \$4.4 million in cash, \$10.7 million in income bearing savings accounts, \$1.8 million in government bonds and \$2.68 million in corporate bonds.

CHARITABLE PURPOSE

During 2014, ALS Canada invested \$1.17 million in new research grants, with an additional \$250,000 provided by Brain Canada matching funds. A further \$381,000 was spent by ALS Canada to support the Canadian ALS research community.

By the end of 2014, ALS Canada held \$15.8 million to fund future research into identifying a cause, treatment and cure for ALS. With the additional \$10 million matched funding available through Brain Canada, this represents a \$26 million research investment opportunity.

In Ontario, \$1.39 million was utilized to provide client support through the equipment program and support groups, plus individual support for clients and caregivers. Advocacy at the federal government level and generating awareness of ALS were other areas of investment.

REVENUE & FUNDRAISING EXPENSE

Management carefully monitors the entire fundraising portfolio and the associated expenses to ensure there are stable revenue streams available to fulfil the charitable purposes of the organization. This is typically a balance between stability in the revenue source, which is generally related to higher cost tactics and lower cost activities which tend to have a higher risk.

Outside of the *ALS Ice Bucket Challenge*, ALS Canada raised over \$6.2 million through direct fundraising activities. 2014 represented the 14th year of ALS Walk events across Canada, with the net proceeds invested in

provincial Client Services (60%) and in Research (40%). In Ontario, the WALK for ALS raised almost \$2.1 million, which was the most ever raised in Ontario through the ALS WALK events, and an increase of over 20% from the previous highest raised. On regular fundraising expenses outside of the *ALS Ice Bucket Challenge*, ALS Canada has a fundraising ratio of 24%, which is within acceptable charity sector and Canadian Revenue Agency (CRA) standards.

An additional \$947,668 was provided through the generosity of the ALS Societies in each province through their WALKS for ALS and additional giving. HealthPartners also represented a significant funding opportunity, with \$194,164 provided through the generosity of employees in federal government offices across Canada.

ADMINISTRATION

2014 administrative expenses were \$553,447, representing an expenditure ratio of 8%. Expenses were \$67,901 (11%) less than the previous year.

GOVERNANCE

ALS Canada is fortunate to have a governance model, which includes a skills-based Board, with Directors from across Canada. In 2014, the Directors met in person four times and held regular monthly teleconferences as well as additional calls as required. Out of pocket expenses are reimbursed relating to travel and accommodation; however no compensation is provided for the countless hours of volunteer time they generously provide. In 2014, the members of the Board also made generous donations personally and through their corporations to ALS Canada and many to the ALS Society in their province.

Overall, 2014 was a year of significant financial change; presenting the ALS community with new opportunities which were unimagined just a year ago. The generosity of Canadians through their amazing participation in the *ALS Ice Bucket Challenge* phenomenon has made it more certain than ever that ALS will soon be a treatable, not terminal disease.

STATEMENT OF FINANCIAL POSITION

DECEMBER 31, 2014

	General Fund	Research Fund	Tim E. Noël Endowment Fund	2014 Total	2013 Total
Assets					
Current					
Cash	\$ 14,796,074	\$ -	\$ 312,000	\$ 15,108,074	\$ 1,300,962
Short-term investments	425,964	-	509,997	935,961	1,104,047
Accounts receivable	1,526,934	-	-	1,526,934	534,125
Inter-fund transfers	(16,531,817)	16,557,119	(25,302)	-	-
Prepaid expenditures	103,491	-	-	103,491	127,132
	320,646	16,557,119	796,695	17,674,460	3,066,266
Long-term investments	2,812,567	681,179	503,305	3,997,051	4,792,403
Capital Assets	113,020	-	-	113,020	182,359
	3,246,233	17,238,298	1,300,000	21,784,531	8,041,028
Liabilities					
Current					
Accounts payable and accrued	568,616	-	-	568,616	372,776
Current portion of deferred revenue	56,354	2,188,203	-	2,244,557	125,071
Current portion of research grants payable	-	1,179,998	-	1,179,998	1,135,831
Current portion deferred lease inducement	29,663	-	-	29,663	25,722
	654,633	3,368,201	-	4,022,834	1,659,400
Long-term deferred revenue	1,939,387	9,618,253	-	11,557,640	-
Long-term research grants payable	-	265,000	-	265,000	589,998
Deferred lease inducement	27,191	-	-	27,191	61,486
	2,621,211	13,251,454	-	15,872,665	2,310,884
Net Assets	\$ 625,022	\$ 3,986,844	\$ 1,300,000	\$ 5,911,866	\$ 5,730,144
Net assets represented by Surplus	\$ 625,022	\$ 3,986,844	\$ 1,300,000	\$ 5,911,866	\$ 5,730,144

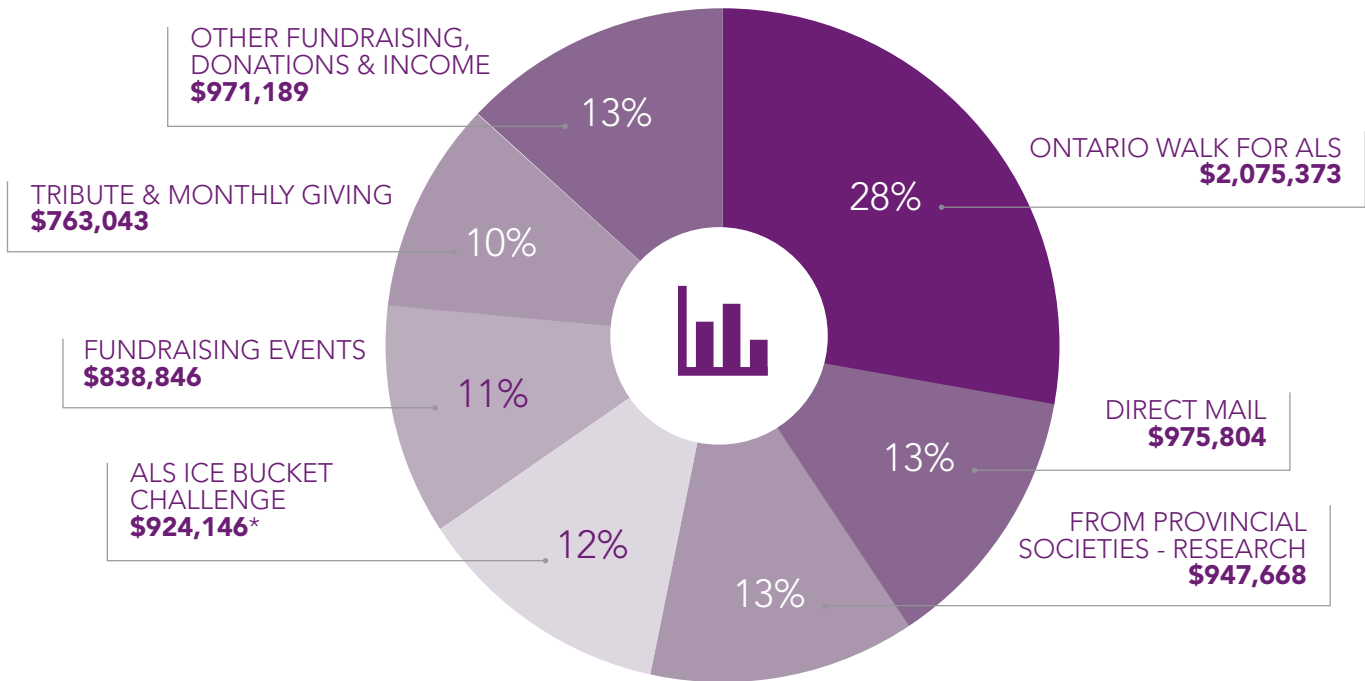
ALS SOCIETY OF CANADA
STATEMENT OF OPERATIONS
 DECEMBER 31, 2014

	General Fund	Research Fund	Tim E. Noël Endowment Fund	2014 Total	2013 Total
Revenue					
Fundraising and donations	\$ 4,423,458	\$ 1,744,784	\$ -	\$ 6,168,242	\$ 5,260,709
Direct mail campaign	965,488	10,316	-	975,804	1,187,956
Interest and investment income	-	147,739	59,976	207,715	193,459
Project grants	43,600	61,931	-	105,531	152,668
Unrealized gain(loss) on investments	81,524	(6,187)	(36,560)	38,777	(102,819)
	5,514,070	1,958,583	23,416	7,496,069	6,691,973
Expenditures					
National research grants	-	1,170,000	-	1,170,000	1,462,667
National research support	-	381,313	-	381,313	456,348
National federation services	228,573	-	-	228,573	245,373
Ontario client support services	1,393,944	-	-	1,393,944	1,431,777
Public awareness	433,061	-	-	433,061	402,904
Volunteer and organizational development	153,204	-	-	153,204	264,795
Project grants costs	43,600	61,931	-	105,531	152,668
	2,252,382	1,613,244	-	3,865,626	4,416,532
Other					
Fundraising	2,520,372	197,600	-	2,717,972	1,749,726
Administrative	553,447	-	-	553,447	621,348
Governance	177,302	-	-	177,302	176,933
	3,251,121	197,600	-	3,448,721	2,548,007
	5,503,503	1,810,844	-	7,314,347	6,964,539
Excess (deficiency) of revenue over expenditures	\$ 10,567	\$ 147,739	\$ 23,416	\$ 181,722	\$ (272,566)

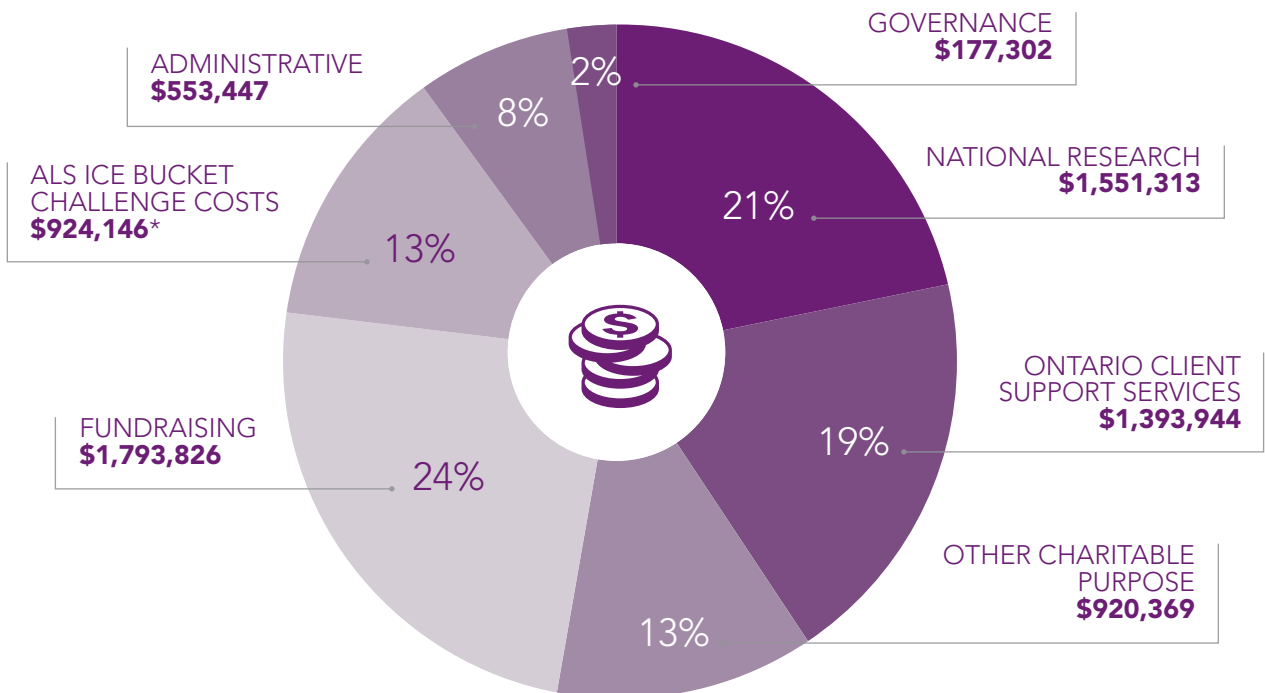
ALS SOCIETY OF CANADA
STATEMENT OF CHANGES IN NET ASSETS
 DECEMBER 31, 2014

	General Fund	Research Fund	Tim E. Noël Endowment Fund	2014 Total	2013 Total
Balance, beginning of year	\$ 614,455	\$ 3,815,689	\$ 1,300,000	\$ 5,730,144	\$ 5,593,476
Transfer of Assets from ALS Ontario	-	-	-	-	409,234
Excess (deficiency) of revenue over expenditures	10,567	147,739	23,416	181,722	(272,566)
Inter-fund transfers	-	23,416	(23,416)	-	-
Balance, end of year	\$ 625,022	\$ 3,986,844	\$ 1,300,000	\$ 5,911,866	\$ 5,730,144

2014 REVENUE



2014 EXPENDITURE



*Deferral method: ALS Ice Bucket Challenge revenue and expenses matched (page 15)

SUPPORTING CANADIANS
LIVING WITH ALS &
INVESTING IN RESEARCH
TO MAKE ALS A **TREATABLE**
NOT TERMINAL DISEASE



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