



OUR MISSION

ALS Canada is committed to:

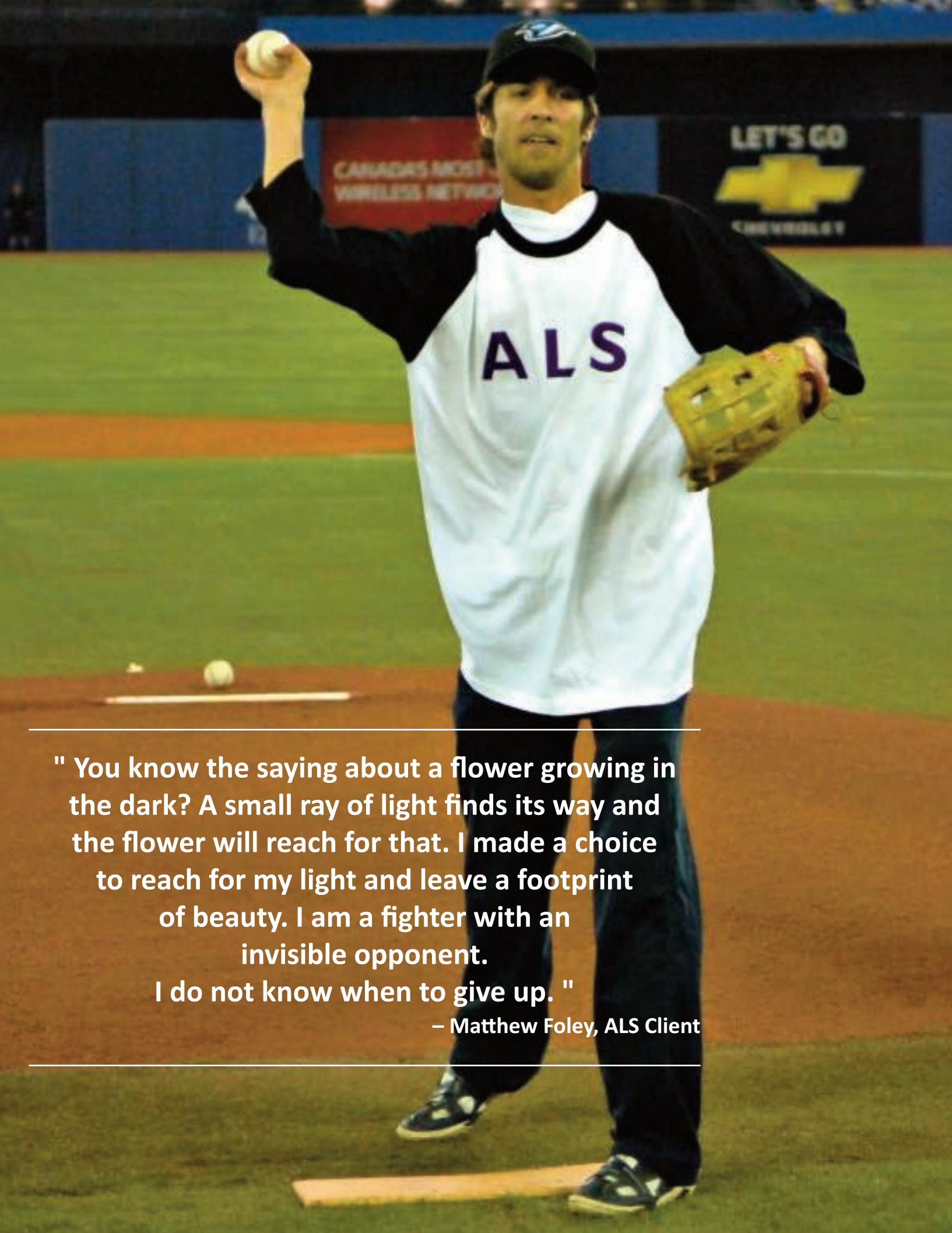
- Support research towards a cure for ALS.
 - Support provincial ALS societies in their provision of quality care for persons living with ALS.
 - Build public awareness of ALS and its impact.
-



Power Through Collective Action



ALS CANADA
2013 ANNUAL REPORT



" You know the saying about a flower growing in the dark? A small ray of light finds its way and the flower will reach for that. I made a choice to reach for my light and leave a footprint of beauty. I am a fighter with an invisible opponent. I do not know when to give up. "

– Matthew Foley, ALS Client

POWER THROUGH COLLECTIVE ACTION

As Chair of ALS Canada's board, I have witnessed over the past year the power of collective action as our staff and volunteers focus to deliver on our organization's key areas: **Cure, Care and Collaboration.**

The ALS Community in Canada is a strong, collaborative team. World-class researchers are a part of that team. This year, members of ALS Canada's Scientific & Medical Advisory Council (SMAC), the Board of Directors and ALS Canada staff developed a comprehensive research strategy and set the direction on how we can work together to accelerate finding a therapeutic discovery for ALS. As a result, ALS Canada will focus our research program on translational research. We will continue to be a part of world-renowned research initiatives with a clear goal: advance ALS Research from bench to bedside.



" We are a collective committed team and continue to work together to make life better for people living with ALS across Canada "

We have also continued to focus our Client Services division on providing consistent quality programs and service to clients and families across Ontario. We've connected to clients, bringing them into the conversation on how we can best meet their growing needs. The collaboration and feedback has been invaluable and has given ALS Canada insight to enhance existing programs to meet those needs.

ALS Canada's Federation Council, representing each provincial ALS Society across Canada, has developed working committees to strengthen and build new programs that will make a difference for clients and families across the country. Working together, the ALS Societies across Canada continue to ensure people with ALS and their families receive the support and assistance they need.

We have increased our organizational capacity and expanded our senior volunteer talent pool to include six new board members: Josette Melanson, Dyana McLellan, Jane Williamson, Dr. Lorne Zinman, Tammy Moore and Melanie York—who all bring a multitude of diverse skills and expertise.

Thank you to the volunteers and donors who have dedicated their time, talent and resources to collectively power our organization forward in support of our clients and families from coast to coast.

Sincerely,

Lanny McInnes, Chair



ALS Canada has firmly planted the foundational work to anchor the organization towards a sustainable future. In 2013 we broke new ground through the power of collective action across the ALS Community. Strengthening our client relationships to deliver on a better service model; collectively harnessing

ideas from the research community to build a strategic framework towards a new vision; forming collaborative programs along with the members of the Federation; all poised the organization to be positioned to take bold actions needed for clients and families living with ALS.

And it was this ground work that was the impetus to elevate ALS Canada's client service model to better address clients' needs. We did this through collaboration with our clients. Clients provided us feedback on what was working and what wasn't and stemming

" Our Inspiration to Excel Comes from The Clients We Serve "

from those conversations the Client Services model was changed to reflect what was needed in our programs. The results were astounding. This year alone, over 1100 clients in Ontario were provided access to home care, palliative care or long term care.

Awareness and advocacy were also key priorities. Thanks to volunteers and donors, the word spread amongst national communities about ALS, raising millions of dollars to support clients and fund ALS research.

It is the ALS Canada research program, made up of a world-class research community, that this year came together and built a new vision for our future: to discover a new therapeutic breakthrough, through a national network, for ALS by 2017. As a team, we will succeed.

In review of this year, I am extremely proud of the depth and scope of our work that has been accomplished. It is because of an entire community: researchers, clinicians, volunteers, our board of directors and donors that make ALS Canada a leading organization.

Sincerely,

Lindee David, Chief Executive Officer



STRENGTHENING RELATIONSHIPS



“ We are not diminished because we have ALS. We will not be defined or swallowed up by this disease. We are and will always be exceptional human beings”

Melanie York, ALS Canada Board Member

ALS Canada’s client services are delivered by a compassionate team of professionals focused on meeting the needs of ALS clients and their families. This year we worked together to strengthen relationships with our community partners in palliative care, hospice, community care and occupational therapy to deliver quality programs and services.

This was the year we engaged clients and families, conversing and soliciting opinions regarding our service model. We embarked on gathering quantitative data from clients on two key areas: the ALS equipment program and overall client experiences. The information gathered was invaluable and was the precipice to improve both areas within the organization.

We are committed to working together as a unified unit. It is because of the collective action of the entire Client Services team that has been the catalyst for ALS Canada to be able to increase services to clients and caregivers, and enhance the knowledge of community personnel about ALS. Of the 1117 Ontario clients registered with us, 923 clients and their family members received direct service.

A Year in Review for Client Services

The year started with an internal review to improve the way we delivered our services. As a result of that review, we introduced a new service model that re-aligned the service regions of our current resources in accordance with the local Community Care Access Centres. The purpose: to ensure a Regional Manager was available to all clients regardless of where they lived in the province.

We embarked on a six month quantitative study of the equipment program, soliciting feedback from clients around satisfaction levels from our services, the equipment they received and knowledge of resources ALS Canada provided.

Did you know clients who have a household income of less than \$80,000.00 and require seating devices through ADP can receive funding from ALS Canada.



Learnings

- 97% of respondents were very satisfied or satisfied with timeliness and advanced notification for equipment delivery
- 100% of respondents indicated the equipment loan pool has been of value to them
- Clients learned about the equipment program primarily from ALS clinic staff and Occupational Therapists

Two common themes emerged: 1 – inability to access information regarding equipment available 2 – concerns that equipment delivered did not meet the client’s needs.

Response

In response, we created a pilot project in Toronto that changed the logistics of our equipment program moving it from a loan pool model to a rental/purchase program. Accomplished by partnering with Shoppers Home Health Care (SHHC), this new model has delivered: eliminating a delivery fee, decreasing the transaction time to receive equipment in seven days and decreasing equipment maintenance.

During this time clients also started to receive their own personal custom seating system. We worked in conjunction with Occupational Therapists to ensure clients received the right seating the first time.

Milestones

A pictorial list of equipment was placed on the ALS Canada website, to provide clients better insight into what the medical equipment looks like and what equipment was available.

We launched a pilot transportation fund for clients living in the Durham region. The fund set at \$500 per client is used to assist clients in covering transportation costs to attend medical appointments.

Ontario Client Services in Numbers



A COLLECTIVE VOICE



"I'm still struggling with the profound implications of what this disease will do to me and my wife and two teenage kids. The prospect of what awaits me as this illness takes hold is terrifying. Our lives are being torn apart, and to add to the emotional burden we also face significant care expenses that are not covered by the medical system that we have come to rely on."

Brian Parsons, diagnosed with ALS in May of 2013

Over **\$150,000**
in costs (direct and indirect)



In comparison with other neurological diseases, such as Parkinsons or severe dementia, patients with ALS have substantially higher out-of-pocket expenses (mostly due to home renovations and mobility equipment)

\$49,108

direct costs for the average course of the disease (3.4 years) (home renovations, mobility equipment, medications, medical devices and services such as portable ventilators, physical therapy)



Expenses are comparable between patients with private insurance and those without, indicating that even for those with the benefit of private insurance, there are substantial unmet needs

\$36,467

indirect costs annually (lost income for the patient and family members)

Once again, we visited officials in Ottawa to lobby for reform to the Compassionate Care Benefits (CCB) policy. This disease has exorbitant financial repercussions and as an organization we continue to use the power of our collective voice to reinforce to the federal government that action must be taken to help caregivers with the direct and indirect costs for caring for an ALS patient.

POWER ON THE HILL - WHAT WE'RE LOBBYING TOWARDS

- Align the Compassionate Care Benefits with the Parents of Critically Ill Children Benefits to address the financial needs of ALS caregivers. This means adjusting the benefit period from 6 to 35 weeks.
- Establish a matching contribution of \$1.5 million per year from the federal government to the ALS Canada Research Program through a Rare Disorder Strategy.
- Build more flexibility into the program, such as allowing partial weeks over a longer period, rather than blocks of weeks at one time.
- Revise eligibility criteria: change the terminology for people eligible for benefits from "significant risk of death" to "significant need of caregiving because of a fatal illness."
- Create a companion program to the Compassionate Care Benefit that is not based on employment.
- Currently, only family members can use/take the Compassionate Care Benefit. Because of the devastating and progressive nature of ALS, the care needs to be shouldered by more than one person. We propose the benefits be split amongst them over a 52-week period.



If you are thinking of donating money for a good cause, donate to ALS research. You'll be glad you did. You will know when you get hit with this disease, and more and more people are, you will want to make sure that we make progress on the research so that ALS patients have a hope for survival

– Zehra Madenli, ALS Client

A NEW DIRECTION

2013 was a transformational year for the ALS Canada Research Program positioning Canadian scientists to make a huge impact as we move into the future

Your donations and tireless fundraising has had a tremendous impact on the global effort towards finding new treatments for ALS. In 2013 we were able to get our first glimpse into the extent of that impact. Canadian ALS researchers not only publish more high quality data per capita than any country in the G8, but the overall impact of our discoveries ranks fourth in the world behind only Italy, Japan and the United States. Canada possesses several world-renowned ALS researchers, and has a number of young up-and-comers and established scientists in other fields who are using their expertise to help solve the riddles of this disease.

Simultaneously, ALS Canada has been increasing our focus on clinical research by:

- Helping to establish the Canadian ALS Research Network (CALS) in 2008 and assisting in their infrastructure to bring the top experimental therapeutics to Canadians through participation in clinical trials
- Funding young neurologists to train in ALS research through our Clinical Research Fellowships (Betty Norman and Bernice Ramsay). This program has assisted two new ALS neurologists to begin treating people with ALS in areas with previously unmet needs
- Nurturing the development of an ALS component in the Canadian Neuromuscular Disease Registry (CNDR)

Creating the Tools for Success

In 2012 we explained that the recent discovery of prominent new gene mutations that cause ALS would open the door to new breakthroughs and targets for therapy. It has become apparent that the four most prominent proteins (products of genes) causing ALS are SOD1 (1993), TDP-43 (2006-2008), FUS (2009) and

C9ORF72 (2011). Researchers continue to learn more about SOD1 in ALS and are getting closer to determining how TDP-43 and FUS work at the molecular level. 2013 was a big year in C9ORF72 research. Not only were the first animal models of this gene mutation created, but we started to see unique aspects of what exactly it (a mystery protein prior to the late 2011 discovery linked to ALS) does.

With rapidly moving research on each of these fronts, combined with discoveries related to less prominent gene mutations in ALS that are pointing towards similar mechanisms, it should be only a matter of time before key connections are made and new targets for therapy are identified.

Setting the Stage for the Future

This was the year, ALS Canada embarked on its first ever Strategic Planning session for research. Members of our Scientific & Medical Advisory Council (SMAC), Board of Directors, our CEO Lindee David and Director of Research Dr. David Taylor gathered with a facilitator in Toronto and built the strategic foundation for the future of ALS Canada's Research Program – Translational Research.

What is Translational Research?

Translational research is designed to facilitate basic research discoveries to reach the clinic and ultimately speed up the progression of new discoveries from bench to bedside. Our vision: to develop at least one novel therapeutic strategy through a national network by 2017.



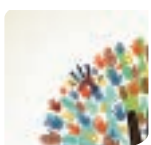
“ This is a landmark year for ALS Canada as we take action to move forward stronger than ever. We are aiming high because the time is now. The challenge is to raise the funds needed to support developing at least one novel therapeutic strategy through a national network to slow the progression of ALS by 2017. We are all advocates of the cause. ”

Dr. Heather Durham,

**Chair of ALS Canada Scientific and Medical Advisory Council (SMAC),
Professor at Montreal
Neurological Institute, McGill University**

Our Research Vision

To develop at least one novel therapeutic strategy through a national network by 2017



CONNECTION THROUGH CALS



**Lorne Zinman, MD, MSc, FRCPC Chair,
Canadian ALS Research Network (CALS) Director**

**ALS/Neuromuscular Clinic
University of Toronto
Sunnybrook Health Sciences Centre**

2013 was a big year for CALS as we were involved in major multi-national, industry-led clinical trials at several sites across Canada. One of these trials, investigating the effect of a drug called Ozanezumab from the company GlaxoSmithKline, finished recruiting in 2013 and we will continue to provide treatment in 2014 as part of the study. This treatment is designed to help keep the connection between the muscle and motor neuron stronger.

Looking ahead to 2014 we have some tremendous things to be excited about. First, we will begin to tackle development of the long discussed Canadian Clinical Practice Guidelines. While US guidelines exist, we believe these can be expanded upon and there are items unique to Canadian ALS clients that can be further explored. ALS Canada will provide support for this initiative and Dr. Christen Shoesmith of London Health Sciences Centre will lead a working group consisting of ALS clinicians from across Canada who will drive the project to completion. In addition, a new Phase II clinical trial should be underway in 2014 that will be the first ever CALS-led clinical trial. Such a study will provide further proof of our ability in Canada to do translational research and test Canadian discoveries in the clinic. As our network strengthens with each passing year, we will continue to strive towards bringing the best experimental therapeutics to Canadian clinics for our clients to access.



GREAT CANADIAN RESEARCH PERFORMED IN 2013

Dr. Blair Leavitt, University of British Columbia

Demonstrated that modifications to muscle can have a definite affect on survival of motor neurons and connections at the place where they connect to muscle (neuromuscular junction). It was discovered that a certain substance found in muscle called myogenin was beneficial towards motor neuron survival and function, while another called MyoD had the opposite effect. This work identifies two potential targets for therapy: one to try and boost and one to try and block.



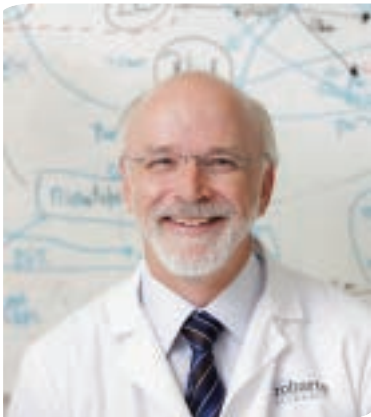
Dr. Geoff Hicks, University of Manitoba

Discovered that the FUS protein, formed from the ALS causing gene called FUS, has an important function of being able to regulate its own levels in cells. When there is a mutation in FUS that causes ALS, it loses the ability to perform this self-regulation function and extra FUS protein is produced which could potentially be toxic to motor neurons. This may explain the clumps of FUS found in cells affected by the disease. A similar function was previously discovered for TDP-43, which is also mutated in ALS and may help to identify common mechanisms and targets for therapy.



Dr. Michael Strong, Western University

Identified a new gene mutation that causes ALS. The gene, called ARHGEF28, creates a protein called RGNEF that is important in RNA regulation, which is a commonality amongst many ALS-causing genes. In particular, RGNEF regulates RNA for something called neurofilament light (NF-L), which is important for neuronal structure, integrity and transport of crucial proteins throughout motor neurons. Neurofilament disruption has previously been implicated in ALS and this new discovery forms stronger connections to identify key targets for therapy.



Dr. Alex Parker, Université de Montréal

Published the first C.elegans (worm) model of the most prominent ALS gene, C9ORF72. His work demonstrates that a lack of this gene causes motor neuron degeneration, indicating that the mutation in ALS might be preventing a normal function of C9ORF72 that might be crucial to motor neuron function and survival. These results are in line with similar models in zebrafish by Dr. Edor Kabashi in France and mice by Dr. Kevin Eggan in the United States.



The spirit of collaboration and power through collective action fits very well with the ALS Canada Research Program’s transformation to more collaborative, translational science.

E-Rare-2 Joint Transnational Call on Rare Diseases

This new multinational effort, brought to Canada by the CIHR, is a means of providing funding for rare diseases (defined as having prevalence below 1 in 2000) where researchers often have to compete for scarce resources against more common, heavily funded diseases like cancer, Alzheimer’s disease etc. The competition solicited applications for grants where projects were collaborative between scientists from three or more of the thirteen participating nations. Three years of funding at \$150,000 per year is provided to the Canadian component and ALS Canada will fund half, with the other half being leveraged dollars from the CIHR.

Heather Durham, PhD, Montreal Neurological Institute
Dysregulation of RNA in the pathogenesis of ALS

Collaborators

Canada – Michael Strong, MD, FRCPC, FAAN, FCAHS, Western University
France – Edor Kabashi, PhD, ICM Brain and Spine Institute
Israel – Eran Perlson, PhD, Tel Aviv University

MEET THE 2013 ALS CANADA SCIENTIFIC AND MEDICAL ADVISORY COUNCIL (SMAC)

Heather Durham, PhD

Chair of SMAC and Professor at Montreal Neurological Institute, McGill University

Pierre Drapeau, PhD

Professor and Director of the Department of Pathology and Cell Biology of the Faculty of Medicine at the Université de Montréal

Angela Genge, MD, FRCPC

Director of the Clinical Research Unit and ALS Clinic at Montreal Neurological Institute, McGill University

Sanjay Kalra, MD, FRCPC

Associate Professor at University of Alberta, Neurologist and Co-Director of Edmonton ALS Clinic

Lawrence Korngut, MD, FRCPC, CSCN

Assistant Professor at University of Calgary, Neurologist and Director of Calgary ALS Clinic

Charles Krieger, MD, PhD

Associate Professor at Simon Fraser University, Neurologist

Jasna Kriz, PhD

Associate Professor at Université Laval

Chris Shaw, PhD

Professor at University of British Columbia

Christen Shoesmith, MD, FRCPC

Neurologist and MND Clinic Director at London Health Sciences Centre

Christine Vande Velde, PhD

Associate Professor at Université de Montréal

Yana Yunusova, PhD

Speech Language Pathologist at Sunnybrook Health Sciences Centre and Associate Professor at University of Toronto

Lorne Zinman, MD, FRCPC

Associate Professor at University of Toronto, Neurologist and Director of Toronto ALS Clinic at Sunnybrook Hospital

The ALS Canada Research Fund

Using the funds previously committed to multi-year funding of labs through the Neuromuscular Research Partnership and Bridge Grants, the ALS Canada Research Fund was developed in 2013 to provide two years of funding at \$120,000 per year. These grants were awarded to the highest ranking ALS applications through the Canadian Institutes of Health Research open Operating Grant competition. It was designed to maintain funding of the best ALS research in Canada during a time of transition for our Research Program.

Jean-Pierre Julien PhD, Université Laval

Therapeutic nanobodies for amyotrophic lateral sclerosis

Guy Rouleau, MD, PhD, FRCPC, OQ, Montreal Neurological Institute

Assessment of somatic mutations and repeat instability in known ALS genes

David Stellwagen, PhD, McGill University

The role of TNFalpha in synaptic plasticity and during neurodegeneration

Ronald Peter Griggs Memorial Fellowship in ALS Research

The Griggs Fellowship provides three years of funding at \$55,000 per year. It was previously awarded in 2010 and is designed to support recent PhD graduates to pursue ALS-related studies. This fellowship has been made possible through the generous support of Harvey and Sue Griggs of Toronto. Their \$500,000 investment in ALS research represents one of the largest gifts that ALS Canada has ever received.

Kyle Peake, PhD, Simon Fraser University (supervised by Charles Krieger, MD, PhD, FRCPC)

Bone marrow-derived stem cells as a vehicle for delivery of therapeutic genes into the central nervous system of a mouse model of amyotrophic lateral sclerosis.

“ Your investment has built one of the best ALS research communities in the world.

Now it’s time for science to pay back those efforts by finding ways to slow down ALS.

It’s an exciting era of change ahead. ”

David Taylor
ALS Canada Research Director

Bernice Ramsay Discovery Grants

Since 2008, ALS Canada, has challenged both established and new investigators in the field of ALS research to come up with innovative projects to push the boundaries in the quest to identify the causes of and treatments for ALS. In 2012, a total of \$200,000 was awarded to Canadian-based researchers who rose to the challenge. These awards were made possible by the generous estate of Bernice Ramsay, which provided a \$2.28 million donation to ALS Canada in 2006.

Neil Cashman, MD, FRCPC, CAHS, University of British Columbia (\$100,000)

Mechanisms of extracellular transmission and propagation of misfolded SOD1: implications for ALS pathobiology.

Richard Robitaille, PhD, Université de Montréal (\$100,000)

Restoring in vivo glial functions at the neuromuscular junction in ALS: A global approach.

Canadian Neuromuscular Disease Registry (CNDR)

In 2013, ALS Canada committed a final installment of \$221,000 to the CNDR. Building an ALS registry in Canada provides a central database of client information for helping to facilitate the planning and execution of clinical trials. Led by Lawrence Korngut, MD, FRCPC, CSCN, University of Calgary, the registry is especially critical for a rare disease because broader efforts by the federal government to obtain similar data for all neurological diseases failed to gather sufficient information for ALS.





\$3.6 Million

85 Communities across Canada
WALKED for ALS

EXERCISING POWER ACROSS COMMUNITIES



Jim Hunter ALS Cycle for a Cure \$235,000

Over 100 cyclists rallied together and rode for clients and families living with ALS



Bombardier Plane Pull \$90,000

180 teammates tested their strength and pulled a 37,000lb plane and Conquered



ALS Charity Golf Classic \$80,000

200 Golfers swung their golf clubs in the ALS Charity Golf Classic



Betty's Run for ALS \$204,000

Now in its 18th year, Betty's Run has proudly been a point of convergence for Calgarians to join with Calgary's corporate community in battling ALS and its devastating effects.

Thank you to over 100 third party
Fundraisers who collectively raised

\$360,000

Across Canada, many individuals and organizations generously give of their time to create and host fundraising events and activities to raise money in support of ALS Canada.



THE POWER OF GIVING

Through the power of giving by our donors, ALS Canada has been able to deliver quality programs for clients and fund world-renowned research towards finding a therapeutic discovery for ALS. Thank you for your continued support of ALS Canada. You are truly making a difference for clients and families living with ALS.

Corporate, planned giving, individual, financial portfolios: annuities, charitable trusts, insurance policies, legacy giving, work-place giving, payroll and matching programs are avenues to donate to ALS Canada. We have many donors who help us reach our goals, however, due to space constraints the following pages reflect those who have donated \$1000 or more in 2013.

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Farrell Fine Carpentry
Finesse
Ford Motor Company
Fronrunner Professional Inc.
GoodLife Fitness
Harvest House Ministries
Hickory Dickory Decks
Indian Wells Golf Club
InfoChoice Digital Media
Insite Computer Group Inc.
International Financial Data Services
International Student Guardianship Canada Inc.
Intrigue Design Consulting
Invesco Canada Ltd.
J. Zechner Associates Inc.
Jones Brown Inc.
Kaylan Properties Limited
Kinsmen Club of Brampton/Bramalea
Kwitko Family Foundation
Kylemore Homes
Labatt Breweries of Canada
Language Marketplace Inc.
Lawrence Scott H & S Equipment
Lexus Canada
Local 222 Retirees Union Hall

Lutheran Social Services	Queenscorp Group	T.E. Financial Consultants Ltd.	Torys LLP
Mackenzie Financial Charitable Foundation	Red Apple Stores Inc.	The Charles and Jane Kucey Foundation Fund	W. Clyde Robertson Insurance Ltd.
Martinrea International Inc.	Redbourne Gateway Properties Co-ownership	The Donnée Group	Walmart Canada
McCloskey International Limited	Rockford Tile Contractors 1996 Limited	The Duke on Sydenham	Wheelchair Accessible Transit Inc.
Miller, Saperia & Company	Rotary Club of Kitchener Westmount	The FIT Effect	Wrigley Canada
NexGen Financial	Royal Bank	The Great-West Life Assurance Company	
North Peace Apiaries	Russell Investments	The Herjavec Group Inc.	
Ontario Law Enforcement Athletic Association	Scotiabank	The Ira Gluskin & Maxine Granovsky Gluskin Charitable Foundation	
Ontario Motor Sales Limited	Secura Financial Group	The Johnston Family Foundation	
Ortech Consulting Inc.	Sheraton Gateway Hotel	The KPMG Foundation	
Oshawa West Lions Club	Sigma Promotions	The Streetsville Musicorp Inc.	
Pallett Valo LLP	Somcan	Thunder Bay Police Association	
Paul Chambers Golf Tournament	St. Phillips Bakery	Tillsonburg Lioness Club	
Pendray Farms	State Street - Matching Gift Program	Tim Hortons Advertising And Promotion Fund (Canada) Inc.	
Phi Delta Theta International Fraternity Foundation	Summit Food Service	TM&TA - Transportation Maintenance & Technology	
Port Royal Mills Ltd.	Summit Reforestation & Forest Management Ltd.		
PPG Aerospace	Superior Machining Ltd.		
Presentation Services Audio Visual			

HEALTHPARTNERS BRINGS ALS CANADA INTO THE CORPORATE REALM

For the past 25 years, ALS Canada and HealthPartners have joined forces and have garnered over one million dollars in donations to support clients living with ALS, and fund peer reviewed research through workplace giving.

HealthPartners is a unique collaboration of 16 of Canada’s most trusted charities focused solely on raising funds through payroll deductions and one time gifts from Canada’s employees. “We are honoured to represent ALS Canada as one of our members” says Kelly Nolan, Director of Marketing and Communications at HealthPartners.

As a supporter of HealthPartners, individuals support ALS Canada through workplace giving or by hosting a workplace giving campaign. “We are compelled to support those living with and those caring for people with ALS. We all want a cure. We all want prevention.”

Incidents of chronic disease are rising; affecting our lives, families, and productivity. In fact, costs to the Canadian economy are in the billions. A national survey of 677 Canadian employers in 2011 demonstrates the

importance of workplace wellness. 97 per cent agree corporate success is related to employee health. Furthermore, Top 100 Employers criteria include engagement, health and wellness and opportunities for giving and volunteering as key metrics of success.

Study after study indicates enhanced profits and productivity when employers address health and wellness - providing more than 11 per cent increase over the competition. Employees who are connected to health and wellness initiatives, volunteer and giving opportunities are more loyal and stay longer, work harder and give more to the company. Companies benefit from enhanced productivity, engagement and lower benefits cost.

The role of the workplace is one that is similar to the tradition of community engagement. Isolated in our bedroom communities, our workplace is often our local connection, our social life, and where we volunteer, give and support. Employers now have the opportunity to lead and realize the benefits of this engagement - both in productivity and savings

all while increasing their recognition as solid corporate citizens by supporting their employees and communities.

In every workplace across our country – every day – someone we know or love is dealing with a recent diagnosis or managing a chronic disease that can sometimes be debilitating. In fact, 87 per cent of Canadians are likely to be diagnosed with a major illness or chronic disease such as cancer, heart disease, diabetes, Alzheimer’s, Parkinson’s and others over the course of their lifetime. At HealthPartners, our members believe charities do better when we work together. ALS Canada believes it too. Together, we can save lives.

iii HealthPartners Charities At Work

For more information please visit www.healthpartners.ca and learn how you can raise more dollars for ALS Canada.

2013 BOARD OF DIRECTORS

Thank you to the ALS Canada Board of Directors for their strong leadership and tremendous work performed in 2013.

Lanny McInnes, Chair Manitoba	Dr. Heather Durham Montreal
Genevieve Bertrand, Vice Chair Québec	Graeme Imrie Ontario
Michael Gardner, Immediate Past Chair British Columbia	Cathy Martin Alberta
Pierre Thibodeau Chair of the Finance and Audit Committee New Brunswick	Dyana McLellan Ontario
	Josette Melanson Ontario
	Tammy Moore Ontario
	Nigel Van Loan Ontario
	Jane Williamson Ontario
	Melanie York Ontario
	Dr. Lorne Zinman Ontario

The glue for the Federation Council is clear: Do whatever we can to help clients and families living with ALS.

As a national organization, ALS Canada would not be able to sustain our leadership position without the collective action from the Federation Council. A collaborative synergy between leadership and volunteers, the Federation Council is an integral advocate in delivering support for clients, executing provincial wide fundraising platforms and funding world-renowned research initiatives. Thank you to the Council for their dedication and drive to deliver on providing services to ALS Canada’s clients and families.



Big Hearts Make a Difference

2013 Volunteer awards



Tony Proudfoot Exceptional
Public Awareness
Program Award

Steve Darling



Tony Proudfoot Exceptional
Public Awareness
Program Award

Patrice Roy, Charles
Ménard and Radio-
Canada's Téléjournal
Team



Tony Proudfoot Exceptional
Public Awareness
Program Award

Siobhan Rock and
Laurie Smith (group)



William Fraser Leadership
Development Award

Lori Weir



Tony Proudfoot Exceptional
Public Awareness
Program Award

PGA of BC
(corporate)



Sidney Valo Exceptional
Fundraising Program Award

Don McCusker



Sidney Valo Exceptional
Fundraising Program Award

Shelly Brown and Mary
RoyALS (third party)



Sidney Valo Exceptional
Fundraising Program Award

The Calgary Motor Dealers
Association (group)



Brett Yerex Exceptional
Advocacy Award

Gabriela Merner



Leader of Tomorrow Award

Sam Dean McCuaig



Leader of Tomorrow Award

Lauren Braun



Mary Pollack WALK for ALS
Volunteer Award

Teresa McAdam and
Leslie McAdam



Myra Rosenfeld
Volunteer Award

Lolo Lam



Lifetime Achievement Award

Ellen Mahoney



Lifetime Achievement Award

Al Pettit
(posthumously)



Marcel Bertrand Exceptional
Support Services Program
Award

Michel Bourassa &
Dylan the Dog



Marcel Bertrand Exceptional
Support Services Program
Award

Interconnexion Team
(group)

ALS CANADA REVENUE PERFORMANCE FOR 2013

The accountability that comes with investing the dollars from the generosity of donors, partners and volunteers, is met with integrity and adherence to fiscal efficiencies to ensure dollars are allocated to where they are most needed – our client services and research programs. Full audited statements are available on als.ca

STATEMENT OF OPERATIONS

Year ended December 31, 2013
with comparative figures for 2012

	2013	Restated 2012
REVENUE		
Fundraising and donations	5,342,424	3,486,887
Direct mail campaign	1,187,956	1,060,188
Interest and investment income	193,459	223,797
Project grants	70,952	2,609
Unrealized gain(loss) on investments	(102,819)	(37,301)
	6,691,972	4,736,180
EXPENDITURES		
National Research grants	1,462,667	1,797,307
National Research support	538,063	362,730
National Federation services	245,373	626,638
Ontario Client support services	1,431,777	-
Public awareness	402,904	218,981
Volunteer and organizational development	264,795	131,848
Project grants costs	70,952	2,609
	4,416,531	3,140,113
OTHER		
Fundraising	1,749,726	963,454
Administrative	621,348	235,822
Governance	176,933	544,284
	6,964,538	4,883,673
Excess (deficiency) of revenue over expenditures	(272,566)	(147,493)

STATEMENT OF FINANCIAL POSITION

Year ended December 31, 2013
with comparative figures for 2012

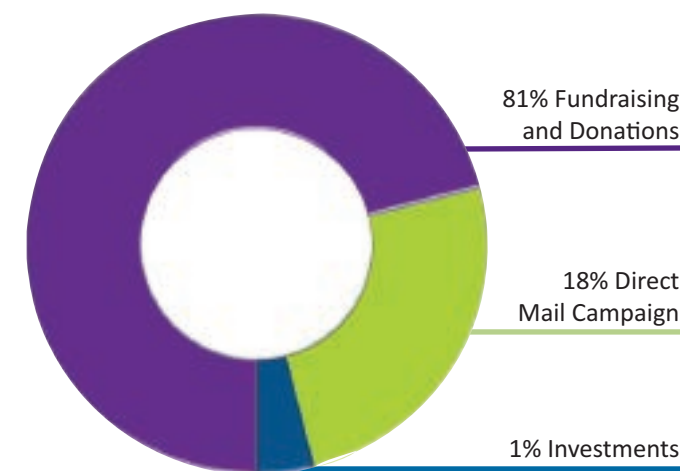
	2013	Restated 2012
Capital assets		
Current assets:		
Cash	1,300,962	302,026
Short-term investments	1,104,047	3,039,993
Accounts receivable	534,125	649,944
Prepaid expenditures	127,132	72,589
	3,066,266	4,064,552
Long-term investments	4,792,403	3,643,569
Inter-fund transfers	-	-
Capital assets	182,359	122,491
	8,041,028	7,830,612
LIABILITIES		
Current liabilities:		
Accounts payable and accrued	372,776	314,105
Deferred revenue	125,071	74,571
Current portion of research grants payable	1,135,831	1,235,131
Current portion deferred lease inducement	25,722	-
	1,659,400	1,623,807
Long-term research grants payable	589,998	613,329
Deferred lease inducement	61,486	-
	2,310,884	2,237,136
Net assets	5,730,144	5,593,476
Net assets represented by surplus	5,730,144	5,593,476

STATEMENT OF CHANGES IN NET ASSETS

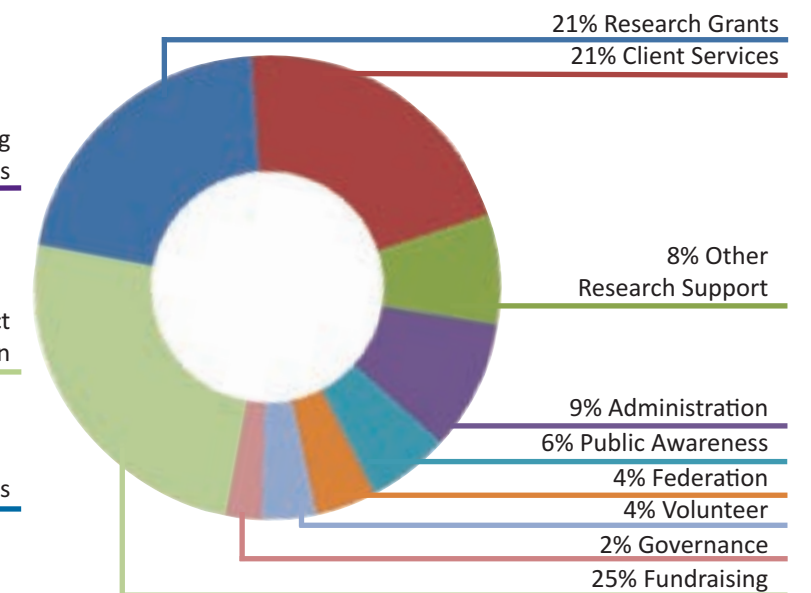
Year ended December 31, 2013
with comparative figures for 2012

	General Fund	Research Fund	Tim E. Noël Endowment Fund	2013 TOTAL	Restated 2012 TOTAL
Balance, beginning of year	250,000	4,043,476	1,300,000	5,593,476	5,740,969
Transfer of assets from ALS Ontario.	409,234	-	-	409,234	-
Excess (deficiency) of Revenue over expenditures	(44,779)	(252,018)	24,231	(272,566)	(147,493)
Inter-fund transfers	-	24,231	(24,231)	-	-
Balance, End of Year	614,455	3,815,689	1,300,000	5,730,144	5,593,476

STATEMENT OF FUNDRAISING REVENUE



USES OF FUNDS



**Thank you for joining us in
the fight against ALS!**