



Amyotrophic Lateral Sclerosis
Society of Alberta
Annual Report
2014



MISSION

The Amyotrophic Lateral Sclerosis Society of Alberta is dedicated to making each day the best possible day for people living with and affected by ALS. We do this by providing support, facilitating the provision of care, promoting awareness, helping find a cure, and advocating for change.

VALUES

RESPECT

We respect the rights, responsibilities, and uniqueness of everyone that we work with and who receive services from the ALS Society of Alberta.

CARING

We demonstrate compassion by listening and providing responsive and practical support.

SERVICE

We serve the needs of people affected by ALS in a fair and equitable manner. We are committed to the continuous improvement of our Society for the betterment of people affected by ALS.

ACCOUNTABILITY

We are responsible for our decisions and actions on behalf of the Society. We demonstrate due diligence in fulfilling our commitments to people living with ALS, their families and friends, our volunteers, donors, and all others who help us support people with ALS.

PASSION

We demonstrate a strong, emotional enthusiasm in our endeavours to make a positive difference in the lives of people affected by ALS. We communicate this enthusiasm to encourage others to share in our vision.

QUALITY OF LIFE

We strive to make every day the best possible day for people living with and affected by ALS by providing the highest level of support and services possible.

BOARD OF DIRECTORS

Tara Pentney

Chair

Retired

Jan Desrosiers

Vice Chair

Retired

Pat Merz

Treasurer

Retired

Nancy Lyzaniwski

Secretary

Manager, Intergovernmental
Relations
Alberta Education

Directors

Heather Haddow

Human Resources
Mount Royal University

Cathy Martin

Senior Consultant, Business
Strategies Branch
Human Services Ministry

Jim McLaughlin

Community and Business Services
Human Services Ministry

Don Pack

Vice President, Operations
Precision Well Servicing

Tracey Wallace, CHRP

Vice President, Human Resources
ATCO Group

Dr. Chris White

Clinical Associate Professor
Department of Clinical Neurosciences
University of Calgary

Dave Williams

Retired

Executive Director

Karen Caughey

MESSAGE FROM OUR HONOURARY CHAIR



JAMES K. GRAY

Every year, I reflect back on the events that have made the ALS Society of Alberta a success in the past year and how they have set the stage for the exciting year ahead.

2014 was certainly a year of great successes. The Ice Bucket Challenge was a phenomenon that we could have never anticipated, but I will continue to be forever grateful for the public awareness and historic amount of funds that was raised to fight this debilitating disease.

\$16.2 million was raised across Canada, with an impressive \$2.8 million coming from Albertans alone. I am still in awe at how this community has come together, and the funds raised will continue to help the ALS Society of Alberta enhance and expand their services so that they can continue to make each day the best possible day for people living with and affected by ALS.

I was also thrilled to learn about the partnership of the ALS Society of Alberta with Mikael Backlund of the Calgary Flames. Like too many others, he and his fiancée have been affected by ALS, and I am grateful for his generous contribution and the attention he has continued to bring to the ALS Society.

The ALS Society of Alberta continues to provide essential services and support to the community because of the tremendous support generated across the province. From their Signature Events like Betty's Run, the 11 Walks for ALS and the annual ALS Charitee Golf Tournament, along with events that are held with the Society in mind, their successes are due in large part to the tireless work of the many wonderful volunteers, their communities, and their donors. I will continue to be impressed at the strength of the ALS community and the dedication that is evident in everything they do.

2014 was a landmark year in the ALS Community and I am excited to see the success continue into 2015.

Sincerely,

James K. Gray, O.C., A.O.E.

MESSAGE FROM OUR CHAIR & EXECUTIVE DIRECTOR



The ALS Society of Alberta had an unprecedented year in 2014. We supported 341 clients and families across the province, the highest number in our 29-year history. We moved into our new combined warehouse and office space in Edmonton to better serve our clients in northern Alberta, and added additional client services staff and staff to our Equipment Loan Program. We embraced the incredible success of the Ice Bucket Challenge with our families in Alberta, Canada and across the world.

The Ice Bucket Challenge created an incredible movement that quickly spread awareness about ALS. It was inspired by one family then grew into a global phenomenon that changed the landscape of research and support for our clients and families. It honoured those who are, or have been affected by ALS, and allowed the disease to become well-known across the world.

We completed our five-year strategic plan, reaching 100 per cent of our goals. Our staff and Board renewed our commitment to clients and families, our mission and values, and the seven pillars of the Society: programs and services, research, advocacy, public awareness, resource development, governance, and management and volunteers.

It is such a pleasure to work with the amazing and passionate staff team, Board of Directors, and with the hundreds of volunteers that continue to dedicate their time to supporting the Society. We simply could not do what we do without you.

It is our unwavering promise to remain dedicated to our mission, and to the people we support.

Tara Pentney
Chair

Karen Caughey
Executive Director

PROGRAMS & SERVICES

Client Services and Supports

We provide support and services to our families through home visits, connecting and accessing community supports and resources, and liaising with allied health care professionals.

341
clients
registered with the
Society

1653
home visits
completed across
the province

1754
pieces of
equipment loaned in
2014

Equipment Loan Program

The ALS Society of Alberta provides mobility and communication equipment for people living with ALS.

Support Groups

Support Groups provide a place for people living with ALS, their spouses, significant others, friends and families. They provide the opportunity to meet others on the ALS journey, share challenges and receive support. Support Groups were held across the province in: Lethbridge, Red Deer, Leduc, Calgary, and Edmonton.

85
support groups held
across Alberta in
2014

42
families
supported through
Support for
Champions in 2014

Support for Champions

The ALS Society of Alberta Support for Champions Program promotes and supports children who have been affected by ALS. The program provides financial support to children and their families to allow them to participate in normal childhood activities.

MOVED
to new office
warehouse space
in Edmonton to
better serve our
Northern
clients.



“We are very fortunate to have an agency like the ALS Society of Alberta. Our mental health is better and we really appreciate not having the financial burden that would be a certainty without the Society. Also, the information is amazing”
- Anonymous

RESEARCH

ON ALS RESEARCH IN CANADA - The summer of 2014 will forever be remembered as the “Ice Bucket Challenge” across the world and in the ALS Community. \$16.2 million was raised in Canada due to the generosity of more than 260,000 Canadians. While the awareness this campaign created alone was astonishing, the impact that these funds have had on research for ALS in Canada are even more impressive.

Funding was announced for a new clinical trial from the donations through the ALS Ice Bucket Challenge and ALS Canada’s partnership with Brain Canada and the Government of Canada. The Arthur J. Hudson Translational Team Grant was first announced on May 3, 2014. This new grant program is designed to fund teams of Canadian researchers to accelerate the movement of ideas out of the laboratory and into the clinic with the hope of assisting development of new therapeutics for ALS.

The first Arthur J. Hudson Translational Team Grant recipient is a team led by Dr. Lawrence Korngut BSc, MD at the University of Calgary and also includes Dr. Lorne Zinman, MD from Sunnybrook Health Sciences Centre and University of Toronto. Together, they will pursue “A randomized controlled trial of pimozide in subjects with ALS”; a Phase II study involving 100 participants across eight ALS clinics across Canada. This trial, led by the Principal Investigator of the Canadian Neuromuscular Disease Registry (CNDR) and the Chair of the Canadian ALS Research Network (CALS) will examine whether pimozide, a drug already approved by Health Canada for use in psychoses like schizophrenia and Tourette’s syndrome, might slow progression of ALS.

2014 ALS Canada Brain Canada Discovery Grant Recipients

Dr. Heather Durham - Montreal Neurological Institute

Epigenetic mechanisms underlying dendritic atrophy in ALS

Dr. Charles Krieger - Simon Fraser University

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

Dr. Alex Parker - Université de Montréal

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

OUR FIRST ANNUAL RESEARCH FORUM



The ALS Society of Alberta hosted the first ALS Research Forums in Alberta, with one event in Calgary and the other in Edmonton. The events were well attended by clients, families and allied health care professionals. Topics included: the basic science of ALS, developments over the past five years, new clinical trials, Canadian innovations as well as cutting edge research.

Dr. Sanjay Kalra MD, FRCPC, Associate Professor for the Centre for Neuroscience at the University of Alberta

Dr. Lawrence Korngut BSc, MD, Neurologist at the Calgary Neuromuscular Clinic, Director at the Calgary ALS and Motor Neuron Disease Clinic and Principal Investigator, Canadian Neuromuscular Disease Registry

Dr. David Taylor, Research Director at the ALS Society of Canada.

RESOURCE DEVELOPMENT

Funding for our programs and services comes from the ALS Charitee Golf Tournament, Betty's Run for ALS, WALKS for ALS, numerous third party events, Alberta Gaming, planned giving & bequests.

In 2014,
Betty's Run for ALS & the WALKS for
ALS raised over \$1,085,389

In 2014,
the ALS Charitee Golf Tournament
raised over \$109,000

The summer of 2014 will forever be remembered as the "Ice Bucket Challenge" across the world and in the ALS Community. Over \$2.8 million was raised by Albertans, with a generous contribution going to research, and the remaining portion staying in Alberta to support and enhance the services provided by the ALS Society of Alberta.



The Honourable
Rona Ambrose,
Minister of Health



Kyle Ruppe's Ice Bucket Challenge with the Stanley Cup

In 2014, over 34 third party fundraisers were held by our amazing volunteers. One of these events was the Rooftop Camp-out for ALS put on by the Lloydminster Fire Department.



The Lloydminster Fire Department braved the freezing weather and camped out on the roof of the fire hall. This amazing support was in honour of a 25 year member of the department who lived with ALS. Citizens of the town donated to the ALS cause in order to convince the firefighters to come down. This event raised over \$19,000 for the ALS Society of Alberta!

PUBLIC AWARENESS



In 2014, Mikael Backlund from the Calgary Flames chose the ALS Society of Alberta as one of his charities of choice. Mikael has shown immense dedication and support across Calgary, and we are so proud to be working with him. Mikael and his girlfriend, Frida are passionate about supporting the ALS cause. Having been touched by ALS, Mikael and Frida have quickly become a strong part of the ALS Community.

Mikael has promoted the ALS cause while personally donating funds for each point he earned over the season. In addition, Mikael generously provided several families with tickets to have a night out and see a game. The ALS Society is thrilled to have such an amazing leader supporting and promoting ALS.

June is ALS Awareness Month!

In 2014 we approached 11 Mayors across Alberta to issue proclamations declaring June as ALS Awareness month in their communities

The Ice Bucket Challenge brought unprecedented awareness to the ALS Cause

In 2014, "ALS Ice Bucket Challenge" was the fifth most Googled term

ALS was in the top 10 percent of Google keyword searches



Howie Sniderman

"We cannot underestimate the awareness that the Ice Bucket Challenge raised about ALS and its impact on all those affected by it. While the funds raised are incredibly appreciated, the Ice Bucket legacy will bring a heightened understanding of what this disease is, what it means to those living with it, and why we focus our energies on support, treatment and research."

- Tara Pentney, ALS Alberta Chair

ADVOCACY

The advocacy efforts of the ALS Society of Alberta are successful and far-reaching to achieve the Mission of “making each day the best possible day for people living with and affected by ALS”. The Society works hard to advocate for awareness and consciousness in government and community support systems. By taking an active role in addressing the need for change within the federal and provincial governments, issues such as increased funding for research, additional comprehensive coverage for equipment and care, more timely delivery of services, and more comprehensive palliative care can be addressed.

In 2014 clients, family members & Board members continued to meet with Members of Parliament as part of the National Advocacy Initiative to increase the Compassionate Care Benefits and improve funding for research in Canada.

GOVERNANCE

The Board of Directors governs the affairs of the Society and sets the vision and mission to serve those living with ALS. The board is made up of 11 passionate volunteers who have all been affected by ALS in some way.

In 2014, the Governance Committee focused on finalizing the content for the second edition of the Strategic Plan, which extends from 2014-2020. A highlight in this process was the joint staff and Board planning day in October, where everyone shared their aspirations and expertise on how to enhance support and services to people living with and affected by ALS. The alignment of purpose and focus of staff and Board members is truly a strength of the organization, and makes it such a privilege to serve on the Board.

The Governance committee also reviewed the policies that provide guidance to our organization and updated them to reflect current realities. The Governance Committee will remain busy as they continue to implement the strategies set out in the new Strategic Plan.

MANAGEMENT VOLUNTEERS & RESOURCES

At the ALS Society of Alberta we strive to manage the organization's human, financial and physical resources in an effective and efficient manner based on clients' needs and priorities. Our wonderful staff and tremendous volunteers continuously contribute to our success. Below are some of the highlights from 2014.

180+
dedicated volunteers
supported the ALS
Society events in 2014

A sincere thank you to all of the volunteers who allow us to continue making each day the best possible day for people living with and affected by ALS. We consider ourselves very fortunate to continue working with such wonderful and dedicated volunteers year-round. We truly could not do what we do without your help, and without the continued support of all our communities.

The Varga and McCachen family received the Tony Proudfoot Exceptional Public Awareness Award for their commitment to *Disabled and Dangerous*, a fabulous film created to raise awareness and funds for ALS.



Volunteer & Long Term Service Awards

Long Term Service Awards

5 years

Marie Nicholson
Staff Member

Heather Haddow
Board of Directors

Provincial Volunteer Awards

Exceptional Volunteer Award
Irwin Vines

Exceptional Fundraising Program Award
Worlds Finest Chocolates

Honourary Life Member Award
Jim McLaughlin

Honourary Life Member Award
Cathy Martin

Exceptional Public Awareness Program Award
CTV

Exceptional Public Awareness Program Award
Global Edmonton

TREASURER'S REPORT



The Ice Bucket Challenge (“IBC”) that took place over the summer of 2014 was a phenomenon that could not have happened if planned. Not only was there over \$16.2 million raised in Canada but also thousands of new ALS donors which translates into a huge growth in awareness of the disease. It was the truly the drive and passion of our clients, families and the community In making the summer of 2014 an incredible game changing impact on ALS! The ALS Society of Alberta’s allocated the IBC funds 70% towards research and 30% towards client services.

The ALS Society ended the year with \$3.05 million in revenues which was a 40% gain over budget and 14.3% over 2013. The amazing Ice Bucket Challenge (“IBC”) event generated strong revenue and significant awareness. The ALS Walks and Betty’s Run in 2014 attributed \$1.3 million or 44% of the total revenues whereas third party events and donations contribute 43% of the total revenue. The other important main stream of revenue the Society continues to focus on is fundraising activities.

Total operating expenses of \$2.7 million represents a 12.8% increase over 2013 which is mainly due to the increase of small equipment purchases, fundraising costs (which included the Ice Bucket Challenge) and increased client services. Client services and the equipment program account for 38% of the total expenditures in 2014 which follows the initiative of the Society’s focused effort & attention to help enhance the service to our clients. Additional capital is also being attributed towards the capital equipment program to better assist our client’s needs. These vital supports and services truly make a difference every day to those living with ALS and their families.

Strong revenue growth and controlled operational expenses in 2014 added to the strong balance sheet that the Society has been maintaining over the past 2-3 years. The Society maintains a very strong liquidity position in their balance sheet with total assets of \$4.28 million and 84% of that being liquid. The management and Board have taken steps in 2014 to better manage their excess cash from operations by using a Discretionary Brokerage company.

The Society continues to strengthen their client equipment program through controlled spending of the bequeathed equipment funds and from cash flows generated by the increased revenue programs. Looking ahead to 2015 we will be increasing our capital spending and continued cost control.

These strong financial results are a reflection of the Society’s strong dedicated staff and group of hard working volunteers that truly make a difference every day in the lives of people living with ALS. We look forward to 2015 being another successful year.

P.J. (Pat) Merz, CGA
Treasurer, ALS Society of Alberta



The ALS Society of Alberta

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Audited Financial Statements are available upon request

ALS.
THREE LETTERS THAT CHANGE PEOPLE'S LIVES.
FOREVER