



2015

ANNUAL REPORT



“Our mission is to make each day the best possible day for people living with and affected by ALS.

We achieve this by providing support, facilitating the provision of care, promoting awareness, helping find a cure and advocating for change.”

MESSAGE FROM OUR HONOURARY CHAIR



James K. Gray
Honourary Chair

Over the years, the ALS Society of Alberta has continued to expand and refine its programs and services to better meet the needs of those affected by ALS. It is my privilege to address the ALS community as Honourary Chair of the ALS Society of Alberta.

The Society experienced incredible growth in 2015. Due to the generous support of donors, additional equipment was added to the Equipment Loan Program, and additional staff was hired for client services, the equipment program and for support throughout the province. The Calgary office reached a significant milestone by beginning the implementation of moving into combined warehouse and office space, allowing for all of the equipment to be stored in a central location. This new space, combined with the warehouse in Edmonton, will make it much easier to respond to the rapidly changing needs of ALS.

The Society also achieved great success with fundraising efforts in 2015. The WALKs and Betty's Run for ALS raised over \$1,007,000, and hard-working volunteers all across the province came together to host events in honour of those affected by ALS. Over 25 third party fundraisers were held throughout the year, allowing for members of the community to come together and channel hope for a future without ALS.

I am greatly looking forward to all that lies ahead for the Society, and am proud to see the strides it has made in making each day the best possible day for those living with and affected by ALS.

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

MESSAGE FROM BOARD CHAIR AND EXECUTIVE DIRECTOR



Karen Caughey
Executive Director

The ALS Society of Alberta had an amazing year in 2015. Alongside our clients and their families, volunteers, donors, staff and our Board of Directors, we continued to live our mission, making each day the best possible day for people living with and affected by ALS.

We implemented our seven-year strategic plan that will guide the Society moving forward by setting a solid foundation on which to grow and build our programs and services. The results from our annual client survey indicated that 81 per cent of responses were very satisfied with the Society's support and services. Although the overall results were positive, we have taken note of the opportunities we can utilize to better meet the needs of our clients and their families.



Jan Desrosiers
Chair, Board of Directors

We held over 95 support groups across Alberta and 1,780 home visits. Our Support for Champions program continued to grow supporting over 47 families. This program allows our families to fund extracurricular activities for their children, helping to alleviate some of the financial burden of the disease.

We also started planning to move our Provincial office into a combined warehouse and office space. This will be a significant milestone for the Society and reflects our commitment to respond to the rapidly changing needs of our clients.

We participated in local, provincial and national initiatives to influence change in policies that impact our families. We are dedicated to our commitment to ALS research and made a significant contribution to national ALS research, allowing for investments in the most promising research initiatives. Together, we will continue to channel hope for those affected by ALS.

BOARD OF DIRECTORS

Jan Desrosiers
Chair

Heather Haddow
Director

Dr. Chris White
Director

P.J. (Pat) Merz
Treasurer

Tara Pentney
Director

Dave Williams
Director

Nancy Lyzaniwski
Secretary

Cathy Martin
Director

Don Pack
Director

Karen Caughey
Executive Director

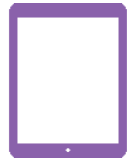
Jim McLaughlin
Director

Tracey Wallace
Director

PROGRAMS AND SERVICES



361 clients supported in Alberta



1,644 pieces of equipment provided



95 support groups held for clients, caregivers, families and children across the province



47 families supported through Support for Champions



1,780 home visits conducted



100% of requests for support fulfilled

EDUCATION PROGRAM



23 educational presentations were provided across the province of Alberta

The ALS Society of Alberta in Partnership with the Huntington's Society of Canada

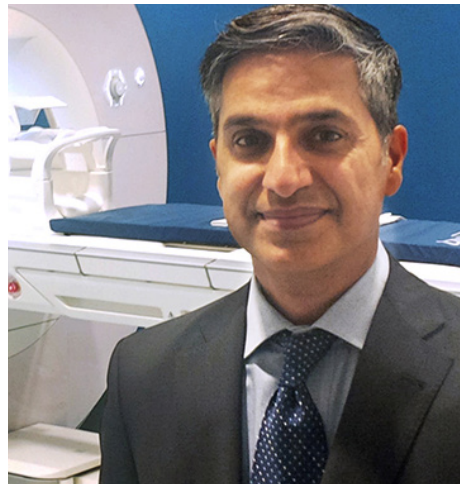
Working in collaboration with the Huntington's Society of Canada and funding provided by Beta Sigma Phi in Calgary, we are refining our education presentations to continue to provide education about ALS. With the generous donations from the Ice Bucket Challenge, we will be initiating an education program that will be rolled out across the province.

CLIENT SURVEY RESULTS

Each year, the Society conducts a client survey to identify both strengths and opportunities for improvement. Questions range from staff knowledge and professionalism, to quality and timeliness of the Equipment Loan Program. The 2015 survey indicated that over 80 per cent of clients were very satisfied with the support services provided by the Society. Although most feedback was positive, the Society will use the results of this survey to identify areas where greater support is needed.



Dr. Lawrence Korngut, Bsc, MD



Dr. Sanjay Kalra, MD, FRCPC



Dr. Amir Sanati Nezhad

RESEARCH

ALS research had an unprecedented year in 2015. The final recipients of the 2015 grant competitions were announced, with the largest grant going to **Dr. Sanjay Kalra**, Professor at the Department of Medicine of the Neuroscience and Mental Health Institute. This \$2.94 million investment will aid Dr. Kalra's research team in the exploration of new high-powered MRI techniques that may be able to diagnose ALS earlier, monitor disease progression and determine treatment efficacy.

Dr. Lawrence Korngut, Director of the ALS and Motor Neuron Disease Clinic, was awarded some of the first financial support for clinical trials taking place in Calgary. He is working to establish pimozide, which is an older medication used to treat psychiatric illnesses, that has looked very promising as a treatment for ALS.

Dr. Amir Sanati Nezhad, Associate Professor at the University of Calgary, was awarded a Brain Canada Discovery Grant to further investigate motor neurons. This study will allow for a better understanding of ALS and potential treatments.

These grant competitions were made possible by the tremendous support during the ALS Ice Bucket Challenge. Albertans raised an outstanding \$2.8 million during the initiative, in which \$2 million was invested into the national research program. Brain Canada then announced that it would match the funds raised for research during the ALS Ice Bucket Challenge, allowing for \$21.5 million to be invested across the country.

One year later, the ALS Societies across Canada are pleased to announce that \$15 million has been invested in the most promising science to aid in accelerating the development of effective treatments for those affected by ALS. These dollars funded 56 investigators at 15 universities across the country.

Funds raised during the ALS Ice Bucket Challenge are fuelling more than 30 research projects across the country. Your donations helped leverage collaborative partnerships amongst the best in the field. Thank you!

\$2 million
donated from the ALS Ice Bucket Challenge

\$342,000
donated from 2015 Betty's Run and WALKS for ALS



ADVOCACY

Since 2013, the ALS Societies across Canada have been advocating for an extension of the Compassionate Care Benefit (CCB) from six to 35 weeks and for eligibility upon diagnosis. In late 2015, the Government of Canada announced the activation of the extension to 26 weeks, effective Jan. 3, 2016. Caregivers can now claim up to \$13,624 in benefits, as opposed to the previous \$3,144.

The Society is hopeful this announcement will relieve some of the financial burden caused by the disease. Although the current extension is a vital step forward, the Societies recognize that better support for families affected by ALS is urgently needed. The Societies across Canada will continue to advocate and influence the federal government to make more meaningful changes to

the CCB and ultimately reach the goal of 35 weeks. This recent announcement indicates that the ALS community's voices are being heard and that the government is responding. The ALS Society of Alberta will continue to advocate for the best possible support for people living with the disease.

GOVERNANCE



ALS Society Staff and Board, October 2015

Strategic Planning

In 2015, the Board of Directors approved a seven-year strategic plan. This plan is a comprehensive and visionary document that recognizes and builds upon the values and strengths of the Society and responds to the current and emerging environment. It is reflective of past successes while remaining dedicated to the future of the Society and those it serves. This plan builds on the previous planning activities conducted by the Society and exemplifies the beliefs and behaviours that are demonstrated daily by the Board, Staff members and volunteers.

The Society bases its strategic and operational plans upon the following seven pillars:

- Programs and Services
- Resource Development
- Research
- Public Awareness
- Advocacy
- Governance
- Management

The Strategic Plan lays out the “broad picture” of the services and operations of the Society over the next seven years, and supports the Society’s mission and values.

“I am very impressed with the dedication that you show towards affected patients and the care that you show towards helping make patients as comfortable as possible! For all that you “all” do, my sincere Thank You! You truly do make a difference.”

- ALS Society Client

RESOURCE DEVELOPMENT

The Society approved its three-year resource development plan in 2015, identifying the concrete goals and objectives to ensure adequate resources are in place to respond to the rapidly changing needs of those living with ALS. This plan works in conjunction with the Society's communication plan to ensure timely access to news, updates and fundraising opportunities.



26 third party fundraisers held across the province



\$537,000+ raised through the Alberta WALKs for ALS



\$470,000+ raised through Betty's Run for ALS



\$20,000+ received through grants across the province



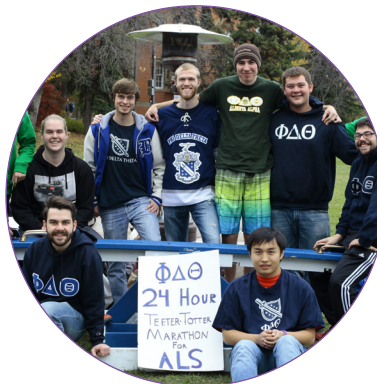
Rose Lecky, Jan Desrosiers, Erin Serack, Karen Caughey, Susan Jones

The Agrium 21-day ALS Ice Bucket Challenge!

In August 2015, Agrium employees showed support for their colleague and friend, Erin Serack, by hosting an unprecedented 21-day-long Ice Bucket Challenge. More than 150 Agrium employees took part in individual and team challenges throughout the month. Not only did the Calgary office turn their parking lot into an ice bucket celebration, but the Carseland plant employees held their own challenge too! Agrium generously matched the funds raised by employees, bringing the grand total to \$69,860!



Songs for Ken, Fort MacLeod



Phi Delta Theta, Edmonton



WALK for ALS, Edmonton

PUBLIC AWARENESS



"The invite to the game and the graciousness of Mikael Backlund was a wonderful day and memory for our family. What an amazing warm and wonderful person to take that kind of time as he understands what families go through. That day was just warm memories for our family that reminds us this challenging journey brings so many special gifts to appreciate in our lives."
- The Thom Family

ALS Ice Bucket Challenge

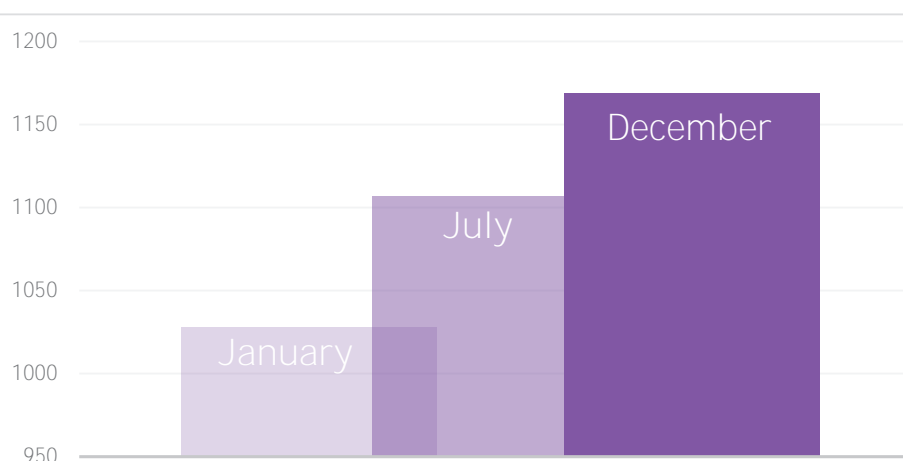
The ALS Ice Bucket Challenge will forever be remembered as one of the most successful social media campaigns in history. August of 2015 marked the one-year anniversary of this monumental event, and the Society celebrated by announcing the fund allocation from the \$2.8 million raised in Alberta. Global, 660News, the Calgary Sun and the Calgary Herald helped spread the message to generous donors across the province, announcing that \$2 million had been invested in research and \$800,000 had stayed in Alberta for client support services. The Society was also able to host a news conference in November of 2015 to announce significant research investments made possible by the ALS Ice Bucket Challenge.

Go Flames Go!

Mikael Backlund renewed his partnership with the Society in 2015, and has been hosting clients and their families at one home game per month. Mikael and his girlfriend, Frida, selected the Society as their charity of choice after being personally touched by ALS. Mikael also makes a generous donation for every point that he earns, and helps to spread awareness about ALS across the sports community. His support both in-person, and online has allowed our content to reach audiences as large as 400,000 people. Thank you Mikael!

Social Conversations

The Society has been able to expand its reach on social media by sparking large-scale conversations about research, policy and fundraising updates. The ALS Ice Bucket Challenge led to a sharp increase in social media followers, and got more people talking about the WALKs for ALS, Betty's Run, advocacy and third party fundraisers. The Society also switched to online newsletters which has presented an opportunity to share essential Society updates with over 400 subscribers.



The growth of Facebook Likes in 2015

MANAGEMENT AND VOLUNTEERS



Impact Day

On October 2, the Society was joined by the amazing staff team from Deloitte Canada. The team worked to audit and refine the Society's existing processes, presenting a detailed report with recommendations for the Equipment Loan Program. This project was part of Deloitte Canada's charitable initiative known as Impact Day, where they take a break from their regular schedule to donate time and resources to non-profit organizations across the country. This project greatly helped define the Society's strengths, and opportunities for improvement.



Kinette Club of Lethbridge



Cathy Martin and Nancy Lyzaniwski,
Board of Directors



Mandy and Judy Van Dresar, Grande Prairie

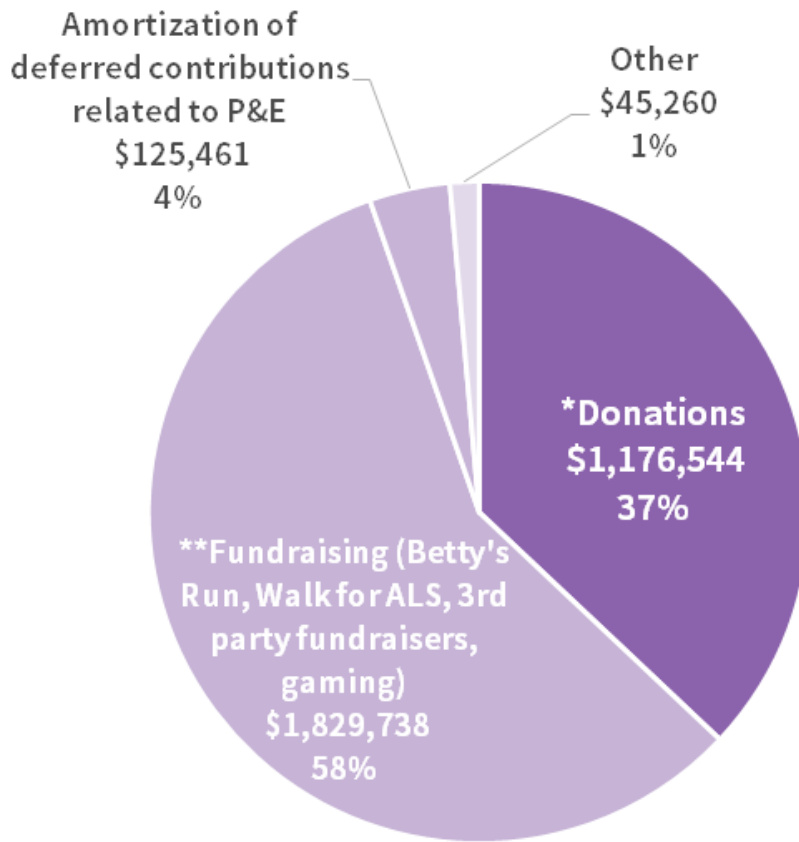
Over 200 volunteers supported the Society in 2015!

These volunteers worked tirelessly to help at fundraising events, in the office with administrative duties, and on-the-ground to help spread awareness about ALS. The Society could not fulfill its mission without the dedication of volunteers across the province, who host heartfelt fundraising events and WALKs for ALS to help bring the community together and celebrate the lives of their loved ones.

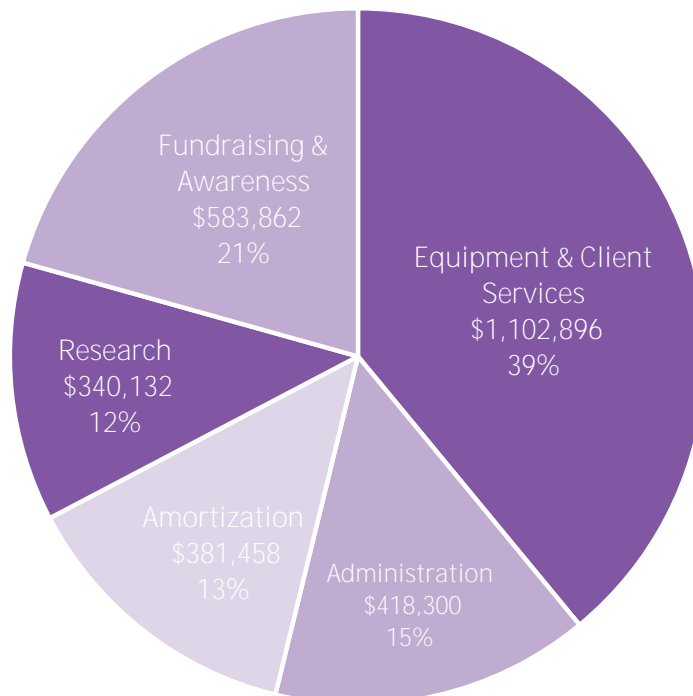
Technology and Infrastructure Update

The ALS Society partnered with F12.net in 2015 in order to bring IT services and processes together and to provide full IT support for staff. This has enabled staff in Edmonton, Red Deer, Calgary and Lethbridge to work within the same systems in real time, which has increased productivity and allowed for an efficient exchange of information.

2015 REVENUE



2015 EXPENSES





The ALS
Society
of Alberta

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