



2016 Annual Report

Amyotrophic Lateral Sclerosis Society of Alberta



Making each day the best possible day for people living with and affected by ALS

Message from Chair and Executive Director

In 2016, the ALS Society of Alberta celebrated its 30th Anniversary. We recognized and expressed our gratitude to the hundreds of families, volunteers, donors and staff over the course of 30 years that contributed to where we are today.

Our supports and services have grown to respond to the ever-changing needs of people living with ALS. It is our families that inspire us to do what we do every day, and challenge us to make a difference.

The results from our annual client survey indicated that generally people are very satisfied with our programs. However, areas of improvement were identified and we have taken time to address the feedback.

In March, the provincial office moved to a combination of warehouse and office space to better facilitate the management of our Equipment Loan Program and to better respond to the rapidly changing needs of our clients.

We are dedicated to our commitment to ALS research and we continue to be the second largest funder of the national program, allowing for investments in the most promising science by cutting-edge researchers.

We greatly value the support of our families, volunteers and donors as we could not do what we do without your support.

“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it’s the only thing that ever has.”

Margaret Mead



Karen Caughey
Executive Director

Karen Caughey



Jan Desrosiers
Chair, Board of Directors

Jan Desrosiers

Message from the Honourary Chair



James K. Gray
Honourary Chair

It is my privilege to address the ALS community as Honourary Chair, and celebrate 30 years of the ALS Society of Alberta providing support to those living with ALS in Alberta.

It was a year full of milestones for the Society. The Calgary office moved into its first-ever combined office and warehouse space, allowing for better control of the equipment inventory and storage. The Equipment Loan Program also received donations to purchase a transport van, allowing for a quick delivery and pick-up of equipment across the province. Combined with the warehouse space in Edmonton, the Society is able to respond to the rapidly changing needs of those affected by ALS faster than ever before.

The Society added a new signature fundraiser in 2016, Bustin' Out ALS, which brought together 250 people from the ALS community for a night of fun. In addition, the WALK for ALS saw tremendous growth, with Edmonton growing to \$352,000 raised and Lethbridge growing to over \$30,000 raised. Altogether, the Alberta WALKs for ALS brought in over \$540,000 for client support services and research. In addition, Betty's Run for ALS raised over \$420,000 and had a record number of attendees join in to celebrate the cause.

I am sure that the successes of the ALS Society will continue, until a cause and cure is found for this devastating disease. I am proud to see the Society live its mission of making each day the best possible day for people living with and affected by ALS.

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

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2016 by the numbers

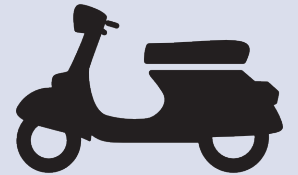
390

Clients supported



1,858

Pieces of equipment provided



30

Educational presentations



1,780+

Home visits conducted



95

Support groups held for clients, caregivers, families and children across Alberta



\$542,000+

Raised through Alberta WALKs for ALS

28

Community events held across the province



21

Families supported through Support for Champions



\$420,000+

Raised through Betty's Run for ALS

Programs and services

In March, the ALS Society of Alberta relocated into combined warehouse and office space in the northeast of Calgary. The move represents a significant achievement for the Society as it is a direct result of over 30 years of donor support. The new facility allows for the Society to better respond to the rapidly-changing needs of those living with ALS, without the need to travel to multiple storage locations.

Support and equipment required during the ALS journey can cost a family up to \$240,000. The ALS Society of Alberta aims to ease this financial burden through the provincial Equipment Loan Program, which has proudly responded to 100 per cent of requests for support. The Society's mission, to make each day the best possible day for those living with ALS, has been strengthened by the warehouse space in Calgary and Edmonton as they allow for all assistive and communicative equipment to be held in a central location.

The Equipment Loan Program is offered free of charge to those living with ALS in Alberta. The Society provides the required equipment along with delivery and pick-up to respond to the rapidly

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“I can't express in words as to what you all did and do for me. I am so grateful for the equipment I receive to make my life so much easier! I am so blown away. It's one thing to deal with this not only physically, but mentally. I think positive and boy, what the ALS Society has done. Thank you from the bottom of my heart.”

”

ALS Society of Alberta Facebook Review, 5 Stars

changing needs of those affected by ALS. The program is available province-wide and lends power mobility devices, assistive communication devices and other medical equipment on a timely basis. The Society is grateful for each and every donor that has made the Equipment Loan Program what it is today.

Combined warehouse and office space, Calgary





Resource development

The Society continued to update its resource development plan throughout 2016. Attention was focused on growing the monthly donor program and increasing the number of community events.

Tremendous growth occurred with the Edmonton WALK for ALS, with over \$352,000 raised. This year featured the James H. Brown Edmonton WALK for ALS Team Challenge, where teams were encouraged to raise more than they did in 2015. The 2016 winner was Tuckwell's Travellers, who raised over \$16,000 more than they did in 2015! The Browns also generously matched \$25,000 of the additional funds raised by teams. Ten additional WALKS for ALS were hosted in 2016 by the Society's amazing volunteers across Alberta.

Betty's Run for ALS celebrated its 20th anniversary, and raised over \$412,000. Over 1,500 people gathered in North Glenmore Park to celebrate the lives of their loved ones, helping to further raise awareness about this devastating disease. Since the beginning of Betty's Run for ALS in 1996, it has grown to raise nearly \$7 million for client support services and research.

The ALS Society of Alberta was thrilled to host its first-ever Calgary Stampede fundraiser at the Ranchman's Cookhouse and Dancehall on July 14. Over 230 people were in attendance, helping the Society raise over \$12,000 through the silent auction and raffle.

“

I soon realized that what I did have was right here, right now. I had a choice to dwell in what might be, or embrace what is. I chose the latter; to embrace my diagnosis. And I am grateful.

Every single day.

”

Erin Serack, 2016 Betty's Run for ALS Ambassador





“

This year was the seventh year hosting Quonset Days in support of the ALS Society of Alberta. Why do we continue to do it year after year? There are many reasons, but the main one being that we want to see an end to ALS. The ALS Society was there with us every step of the way whether it was providing equipment, access to doctors at the ALS Clinics, moral support and so much more. We hope that holding Quonset Days will help the ALS Society of Alberta continue to be the amazing support that those with ALS need.

”

Janet Biemans, organizer of the Quonset Days ALS fundraiser in Seven Persons

Community events

The Society saw an increase in the number of community events held across the province. From concerts to fitness classes, unique ideas were abundant to help raise funds for the ALS Society of Alberta.

John Wort Hannam hosted the second annual Songs for Ken fundraiser in honour of his closest childhood and adult friend, Ken Rouleau, who lived with ALS. When John first learned of his friend's diagnosis in 2011, he began organizing fundraisers to help with the financial burden of the disease.

The annual Big Drew's Big Ride took place on the Legacy Trail between Banff and Canmore. This team of hardworking fundraisers far exceeded their fundraising goal of \$2,500, and raised \$9,400 for the ALS Society of Alberta.

The Lloydminster Fire Department braved the cold weather to host its annual rooftop campout in support of the ALS Society. This fundraiser grows each and every year due to the tremendous support of the fire department and donors within the Lloydminster area. The team raised nearly \$28,000 this year.

The seventh annual Quonset Days music festival took place in Seven Persons, in support of the ALS Society of Alberta. This year's headliners included rising country star, Kira Isabella, Econoline Crush and Bobby Wills! Nearly 1,000 people attended, camped and enjoyed the music.

The ALS Society is grateful for the hard work and dedication of volunteers across the province.





“ALS has taken away my ability to work and enjoy the activities I love. But, ALS has not taken away my will to live. Soon after I was diagnosed with ALS I was introduced to the ALS Society of Alberta.

Wow, lucky me.

John Orfino, 2016 Edmonton WALK for ALS Ambassador”

Public awareness

The ALS Society of Alberta led an awareness campaign throughout 2016 with the theme of “Making it Possible”. This represents the ALS Society of Alberta’s mission to make each day the best possible day for those living with and affected by ALS. Over the month of June (ALS Awareness Month) the Society encouraged the ALS community to share stories of how they were able to make moments and memories possible with the help of their friends, families and caregivers. The “Making it Possible” campaign was launched by the premiere of the Society’s brand new public service announcement, showing the different possibilities that mobility equipment provides for those living with ALS.

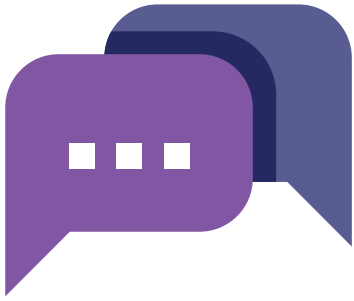


Mikael Backlund of the Calgary Flames and Frida Engstrom continued their work with the Society by choosing ALS as their charity of choice for 2016. Mikael and Frida hosted families affected by ALS at monthly hockey games and visited them up in the stands after the game was over. They also launched an ALS Ice Bucket Raffle at the Scotiabank Saddledome in December where over \$5,000 was raised. This helped spread awareness across the arena, and across the Twitter feeds as fans chipped in to support Mikael and Frida, and the ALS cause.



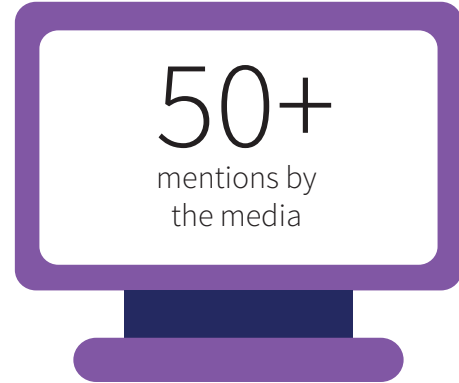
The ALS Society of Alberta continued to raise awareness via social media, and launched both an Instagram and a Snapchat account in 2016.

In the media

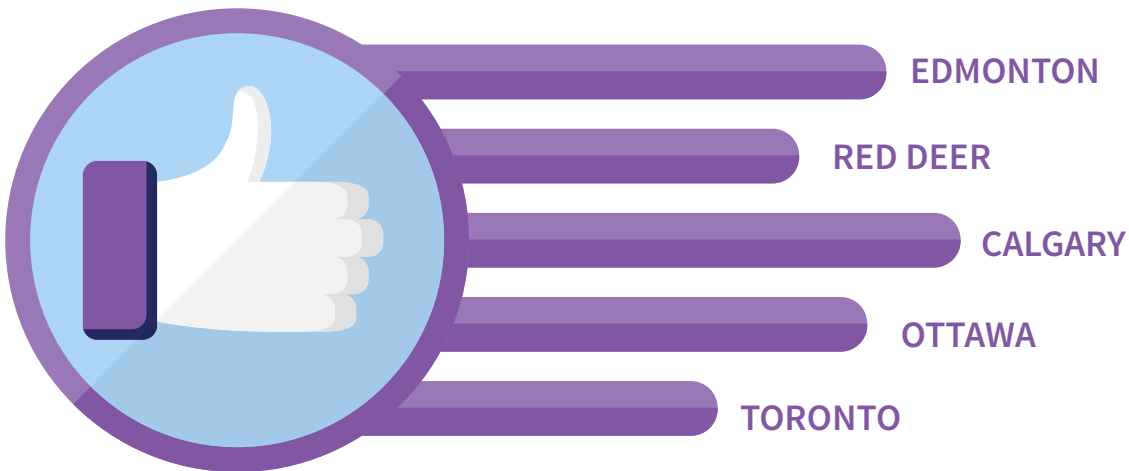


175,000+

people reached through Twitter in 2016



Facebook likes across the country



Exceptional Public Awareness Award

This award is given to someone who provides exceptional programs aimed at educating and raising public awareness about ALS. Su-Ling Goh, of the Global Edmonton Health Matters segment, completed a two-day series about living life to its fullest while faced with an ALS diagnosis. Her respectful and kind approach to our clients and families made a significant impact and inspired hope for those affected by ALS in Alberta.



Management and Volunteers

The ALS Society of Alberta was proud to celebrate its 30th Anniversary in October, in both Calgary and Edmonton. Guests and staff recounted memories of the past 30 years and spoke about the tremendous growth the Society has had due to the generous support of donors, volunteers and supporters. The Society also recognized its outstanding volunteers through the annual ALS Society of Alberta provincial awards. Awards were granted for exceptional fundraising, planning of the WALKs for ALS, public awareness, and volunteerism.

In order to continue to meet the ever-increasing demand of support and services, the Society increased its staffing to include a full time Equipment Assistant in the Calgary warehouse and a full time Client Services Coordinator in Southern Alberta. Across the province, the Society now has a full complement of staff working directly to support families.

In 2016, the Society was chosen to work with the Deloitte for its annual Impact Day. This initiative dedicates a full day of Deloitte's staffing resources to non-profit organizations in Canada, with the goal of improving efficiency of organizational processes. Deloitte assisted the Society in analyzing administrative processes, and identified changes to streamline the Society's work.

In January 2016, Dr. Douglas Cave from the BC Centre of Renewal spent the day working with the staff team to explore ways of supporting each other as they work with some very intense situations. The Society believes it needs to continue to foster and support its staff so they can best support families affected by ALS.





This organization is vital to any person and family that has a personal experience with ALS and they step up to the challenge with compassion and grace, and become fierce advocates for their clients! I'm so very proud to be a supporter.

ALS Society of Alberta Facebook Comment

Governance and advocacy

The annual Board and Staff Planning session was held in October. This joint session brings the Board and Staff together to reaffirm the Society's commitment to its mission, and to look forward into the following year. In 2016, the Board and Staff discussed the organizational culture of the Society in honour of its 30th anniversary, and how the organization has grown as a result of tremendous donor support. The Society could not do what it does without the support and leadership from the Board of Directors. It now holds over 80 years of combined service to the Society.

In 2016, the Society held significant meetings with both the Provincial and Federal Government. In the fall, the Society met with Alberta's Minister of Health to share information about ALS and the Society's client support services. A follow-up meeting was held a few months later with Alberta's Associate Minister of Health.

The Society also met with a key contact from Veterans Affairs to better understand the support services that they have available, and how the Society can expedite the process of its services. Developing and strengthening relationships with Government programs and services helps to best serve those affected by ALS now, and in the future.

The Provincial Advocacy Advisory Group continues to meet on a monthly basis. It advocates for change on behalf of, and alongside people living with and affected by ALS, and develops strategy for issues that require attention.



*Board Member, Dave Williams
Edmonton WALK for ALS*



*Board Members Cathy Martin and Nancy Lyzaniwski
Camrose WALK for ALS*



Research

The ALS Society of Alberta is proud to be one of the largest contributors to the national ALS research program. With the support of its provincial partners, ALS Canada invests into the most promising research to help find a cause and cure for this devastating disease. In 2016, the ALS Society of Alberta contributed upwards of \$340,000 to the program, due to the tremendous success of Betty’s Run for ALS and the WALK for ALS across Alberta.

Alberta is home to some of Canada’s most talented ALS researchers. Due to the tremendous fundraising result of the ALS Ice Bucket Challenge, Alberta researchers have received grants and funding for some of the most promising research in Canada.



Dr. Sanjay Kalra

The Canadian ALS Neuroimaging Consortium (CALSNIC) was founded with the intention of identifying and evaluating MRI biomarkers. This multicentre research platform provides the opportunity for Canadian researchers to address issues

on a national scale. Sites include both the University of Alberta and the University of Calgary, along with five other research institutions across the country. CALSNIC conducts MRI studies of people living with ALS, and with healthy controls. The primary goal is to determine a biomarker that can help diagnosis ALS earlier, creating a multicentre platform for research with an increased capacity. CALSNIC was spearheaded by Dr. Sanjay Kalra of the University of Alberta. Dr. Kalra was the recipient of a \$2.94 million grant, made possible by the ALS Ice Bucket Challenge and matching funds from Brain Canada.



Dr. Lawrence Korngut

Pimozide is a medication that has been demonstrated to enhance communication at the neuromuscular junction (an area where dysfunction occurs between the muscles and the nerves) in fish and mice. Dr. Lawrence Korngut, Director of the ALS

and Motor Neuron Disease Clinic, has been studying whether or not Pimozide may help to slow the progression of ALS and how much medication needs to be taken to have an effect. This project was made possible by the Arthur J. Hudson Translational Team Grant, which brings researchers together from across the country to accelerate therapeutic development.

Project MinE

“Why have I been diagnosed with ALS when so many other people have not?”

This is an all-too-common question of people living with the devastation of an ALS diagnosis. Project MinE is a multi-national initiative with more than 15 participating countries. It will map the full DNA profiles of 15,000 people with ALS and 7,500 control subjects, establishing a global resource of human data that will enable

scientists worldwide to understand the genetic signature that leads someone to develop ALS.

By accumulating such a large amount of data that no one country could achieve alone, it is expected that Project MinE will identify new genetic causes of the disease that will significantly accelerate our ability to advance treatment possibilities that will slow down or stop ALS.



\$ **\$20 MILLION**
has been invested into ALS
research since 2014

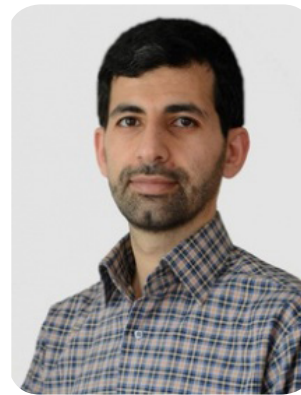


there has been more research
progress in the last 5-7 years
than in the last century

10 Canadian grant programs
currently invest into the
most promising science

The research investments made in 2016 will fund 20 projects across the country, enabling 31 researchers at eight academic institutions to engage in important ALS research. These include:

- With co-funding from Brain Canada (with financial support from Health Canada), two large-scale multi-year team initiatives – one of which is using stem cell technology to better understand and potentially treat ALS, while the other is studying in a new way the gene most commonly linked to ALS development.
- \$1.5 million awarded to early-career researchers through three different grant programs that invest in the future of ALS research by developing the next generation of scientists and enabling them to focus their work on ALS.
- \$700,000 to seven smaller studies, co-funded with Brain Canada (with financial support from Health Canada) that enable investigators to explore outside-of-the-box research.
- The first recipients of the ALS Canada Clinical Management Grant. This program funds research focused on avenues to maximize function, minimize disability and optimize quality of life through symptom management and support to families and persons living with ALS. The funding allowed a group of researchers to explore the use of cannabinoids, substances that have demonstrated therapeutic effects including anti-inflammatory, analgesic, and anti-anxiety, for ALS symptom management.



Dr. Amir Sanati Nezhad

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.



Dr. Kelvin Jones

Dr. Jones is a two-time recipient of funding from the ALS Canada Research Program, which is supported by donors to the ALS Society of Alberta. A major focus of his lab at the University of Alberta is how exercise, or lack thereof, can influence the progression of ALS. Dr. Jones presented his compelling findings in Dublin at the International ALS/MND Symposium in December 2016, enabling ALS researchers from all over the world to learn about this Canadian research.

Treasurer's Report



I am very pleased to report that 2016 was another fantastic year for the Society. The overall revenue position for the Society remains very strong with actual revenue for 2016 totalling just over \$2.9 million. There has been a 7.7 per cent decrease in revenue from 2015 as would be expected from the current economic situation in Alberta.

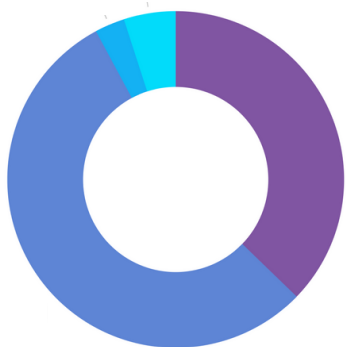
Revenues from Betty's Run, the WALK for ALS and community events continue to be the major source of revenue (55 per cent of total revenue). These, along with generous contributions from our donors and other significant fundraising activities that our staff and volunteers passionately and tirelessly work on, help to fund the important work that the Society does.

The Society continues to place significant emphasis on expenditures for client services and equipment, which includes equipment purchases, repairs and amortization to continue to provide this essential service to our clients.

The total operating expenses of \$3 million is an increase of 6 per cent from 2015 which is mainly due to the key areas of small equipment purchases and client services. These vital supports and services accounted for 51 per cent of the Society's expenditures in 2016. The ALS Society of Alberta continues to be the second largest contributor to national ALS research.

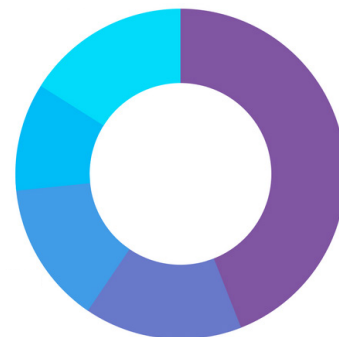
The Society is well positioned for another strong year in 2017.

Gord Banting, CPA, CMA



2016 ALS SOCIETY OF ALBERTA REVENUE - \$2,927,551

■ Fundraising (Betty's Run, WALK for ALS, etc)	54.91%
■ Donations	37.24%
■ Amortization of deferred contribution	4.98%
■ Other	2.87%



2016 ALS SOCIETY OF ALBERTA EXPENSES - \$3,006,630

■ Equipment and Client Services	44%
■ Fundraising and Awareness	16.06%
■ Administration	15%
■ Amortization	14%
■ Research	11%

Thank you!

to each and every donor that allows that has supported the ALS Society of Alberta over the past 30 years.

Together, we can achieve our mission of making each day the best possible day for people living with and affected by ALS, and channel hope for a future without this devastating disease.



The ALS
Society
of Alberta

Celebrating 30 Years



WALK for ALS.ca
Hinton



The ALS
Society
of Alberta

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