



2018 Annual Report

ALS Society of Alberta



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

A message from the Board Chair and Executive Director

Inspiring Care, Hope and Community

Thousands of dedicated Albertans from across the province come together year after year to support the ALS cause.

Honouring loved ones by walking, running, hosting lemonade stands, camping on a rooftop in the middle of winter, hosting an outdoor concert, teeter tottering for days, just to name a few. We hear amazing stories of resilience, hope and community. Most importantly, people want to make a difference in the relentless fight against ALS.

It is because of your generous support we can do what we do without local or provincial government funding.

In 2018, your support has allowed us to expand our client services across the province, further develop our education resources and continue to provide much needed equipment from our loan pool. All at no cost to our families.

The ALS Society of Alberta continues to be the largest funder per capita of national ALS research. Our donation helps to fund clinical trials and new initiatives that has moved research more in the last five years compared to the last decade. Last year, Health Canada approved a new ALS treatment for the first time in 20 years.

It is the collective efforts with our provincial partners and the ALS community advocating collectively to influence decision makers and the generosity of Albertans that continues to make an impact on funding critical ALS research.

We greatly value our partnerships with the ALS Clinics, health care community and home care supports. It takes an entire community to respond to the challenges our families are faced with each and every day. Thank you to our families, volunteers, donors and staff team. We could not do what we do without your generous support and commitment to the ALS community.



Tara Pentey
Chair, Board of Directors

A handwritten signature in black ink that reads "Tara Pentey".



Karen Caughey
Executive Director

A handwritten signature in black ink that reads "Karen Caughey".



BOARD OF DIRECTORS

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Executive Director

A message from the Honourary Chair



As Honourary Chair, it is my privilege to address the ALS Community and to celebrate the achievements of the ALS Society of Alberta. I continue to be inspired by the work of the Society in providing support to those living with and affected by ALS.

Thanks to the generosity of donors and the community, the Society was able to make tremendous strides with fundraising in 2018. The Walk for ALS expanded to include a new location of Drayton Valley, bringing the total number of Walks in the province to 11. Combined, the Walk for ALS raised over \$600,000 in Alberta.

In addition, Betty's Run for ALS raised over \$480,000 toward client services and research.

The Equipment Loan Program continued to deliver and respond to client needs. It is of great comfort to be able to say there is no wait list for equipment and the Society is always able to respond to the rapidly changing needs of those living with ALS. Ensuring the needs of clients are met is a top priority for the organization. The combined office and warehouse space in both Calgary and Edmonton allows for a quick response for equipment needs across the province.

I am looking forward to the continued successes of the Society, and I am proud to see the Society fulfill 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.

2018 by the numbers

435

Clients supported



1,732

Pieces of equipment provided



1,671

Home visits conducted



103

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



48

Community events held across the province



40

Families supported through Support for Champions



11

WALKs for ALS held in Alberta



44

Educational presentations given



100%

of requests for support fulfilled



Programs and services

The foundation of our mission is to make each day the best possible day for people living with and affected by ALS is providing support and equipment for people living with ALS in Alberta.

In 2018, an additional Client Services Coordinator was added to our resource pool to provide greater outreach to our families in Alberta. Client Services Coordinators help families navigate the complex health system and are an integral part of a person's care team. In 2018, we supported 435 families in Alberta and our client services staff reached out through 1,671 home visits.



There has been an increasing demand on our Equipment Loan Program to fill the gaps left by other programs, address the financial burden ALS creates for our families and respond to the rapidly changing needs of the disease. We could not do what we do without the generous support of Albertans. We have over 1,700 pieces of equipment on loan across the province.

The Society was able to support 40 families through the Support for Champions Program. This program allows children whose parents are affected by ALS to participate in regular childhood activities that may not be available to them due to the immense financial burden ALS can cause. Activities range from sporting activities to cooking classes or other activities in which the children are interested in.

Each year, the Society conducts a client survey to identify strengths as well as areas for improvement. Questions range from staff knowledge and professionalism, to quality and timeliness of the Equipment Loan Program. The 2018 survey indicated 86% of clients were very satisfied with the support services provided by the Society.

Governance and advocacy

The board and staff came together in October to reaffirm our mission to make each day the best possible day for people living with and affected by ALS. It was an opportunity to strategize and strengthen our fundraising plan to ensure we can continue to support our families in the future. Susan Storey, Partner with KCI (Ketchum Canada Inc.), facilitated the day and generously volunteered her time to support the ALS Society of Alberta.

A champion advocate, Colleen Kovaluk, along with her husband Peter, took on an unsurmountable task to advocate with the Provincial Government to amend the Local Authorities Pension Plan (LAPP) Regulation to unlock the pension benefits due to considerably shortened life expectancy. Colleen met with LAPP officials, Alberta Government officials, United Nurses of Alberta, the ALS Society of Alberta and Finance Minister Joe Ceci. Nineteen months later, Colleen was informed by Minister Joe Ceci that the amendment to unlock the pension benefits due to considerably shortened life expectancy will be done. This is truly an example of selfless dedication and how creating changes are possible in the face of adversity.

Resource development

Betty's Run for ALS

The 22nd annual Betty's Run for ALS took place on Sunday, June 10 in North Glenmore Park. Over \$486,000 was raised, far exceeding the fundraising goal of \$450,000.

The ALS Society of Alberta would like to thank Ambassador Wayne Thomas for all of his dedication in raising awareness for the Society. The Society would also like to thank Mayor Naheed Nenshi, the 2018 Betty's Run for ALS Planning Committee, and all sponsors, volunteers, donors and supporters. This event has continued to make a tremendous impact in the community.



Wayne stated "From a personal perspective, this diagnosis has been a glaring reminder for me that we all have to savour life more and live it to the fullest. I have had a great life so far, and any experiences I have going forward will be counted as a blessing not a right." "Supporting Betty's Run is a great example of how we can all get involved and I am honoured to be part of it."



\$1,023,286+
raised through the
Alberta Walks for ALS and
Betty's Run for ALS

Walk for ALS

There were 11 Walks for ALS in 2018. The Edmonton Walk for ALS, held on June 9, saw over 1000 people gather together in William Hawrelak Park. The Edmonton Walk for ALS exceeded its fundraising goal of \$380,000.

The Society was honoured to have Adam Rombough as the Edmonton Walk Ambassador. Adam passed away in May, prior to the Walk but had shared these words on Facebook after his diagnosis. "Even though this is a horrible disease, I am not focusing on the negatives, I am choosing to focus on all of the positive blessings that this has brought into my life and I hope that you will too."

Drayton Valley held its first Walk for ALS this year; it was a great achievement raising over \$27,000. The coordinators worked tirelessly organizing fundraisers, raising awareness and promoting the Walk at every chance.



The ALS Society of Alberta would like to thank the Walk Coordinators and volunteers for planning the Walk for ALS in Camrose, Cold Lake, Drayton Valley, Edmonton, Fort McMurray, Grande Prairie, Hinton, Lethbridge, Peace District, Red Deer, and Valley Ridge.

Community events

In 2018, the ALS community held 48 different fundraising events across Alberta. From golf tournaments and concerts to lemonade stands and garage sales, ideas were unique and plentiful and help build awareness and raise funds for the ALS Society of Alberta. These community events make a direct impact in the lives of people living with ALS and help educate more people about this devastating disease.

The Lloydminster Fire Department once again braved the freezing temperatures to host their 6th annual rooftop camp-out in support of ALS. This fundraiser has continued to grow over the years and their continued support is a reflection of the tremendous generosity and compassion of the Lloydminster community.

2018 was the first year of Karen's Purple Shirt Party. This event was started by Karen's family to gather with friends and family to reminisce and spend the day together. Everyone was asked to wear something purple, as it was Karen's favourite colour. Karen's Purple Shirt Party raised over \$22,000.

The Biemans Family held their 9th Annual Quonset Days in July. Since Quonset days started in 2010, they have raised over \$400,000 for the ALS Society of Alberta. We are so honoured to be a part of such an inspiring event.

Big Drew's Big Ride marked its fifth and final year. Event organizer, Jim Robinson, created this event with his best friend Drew, after Drew was diagnosed with ALS. This event brought together over 100 riders that clocked thousands of kilometers along the Legacy Trail and raised over \$58,000! Thank you Jim and all of the participants over the years.

The ALS Society of Alberta is so grateful for the dedication and hard work of volunteers across the province. Thank you to each and every person who organized, attended or donated to these community events. Your support truly makes a difference!



“Having lost a friend and fellow firefighter to ALS in 2013, this cause has been a unifying force for our members and our community. Each year, the support we receive from the residents of Lloydminster warms our hearts in the cold conditions.”
-Lloydminster Fire Chief Jordan Newton



Public awareness

The ALS Education Project moved forward with the research and development of the learning modules. The focus is to provide information and education on ALS in areas of need.

Since 2014, Mikael and Frida Backlund have generously supported the ALS community through donations, fundraising and hosting families at Calgary Flames games. The games are more than a night out, but also creating lasting memories that stay with the family forever. Mikael and Frida give their precious time to generate a greater awareness of ALS and the need for support and to find a cure.

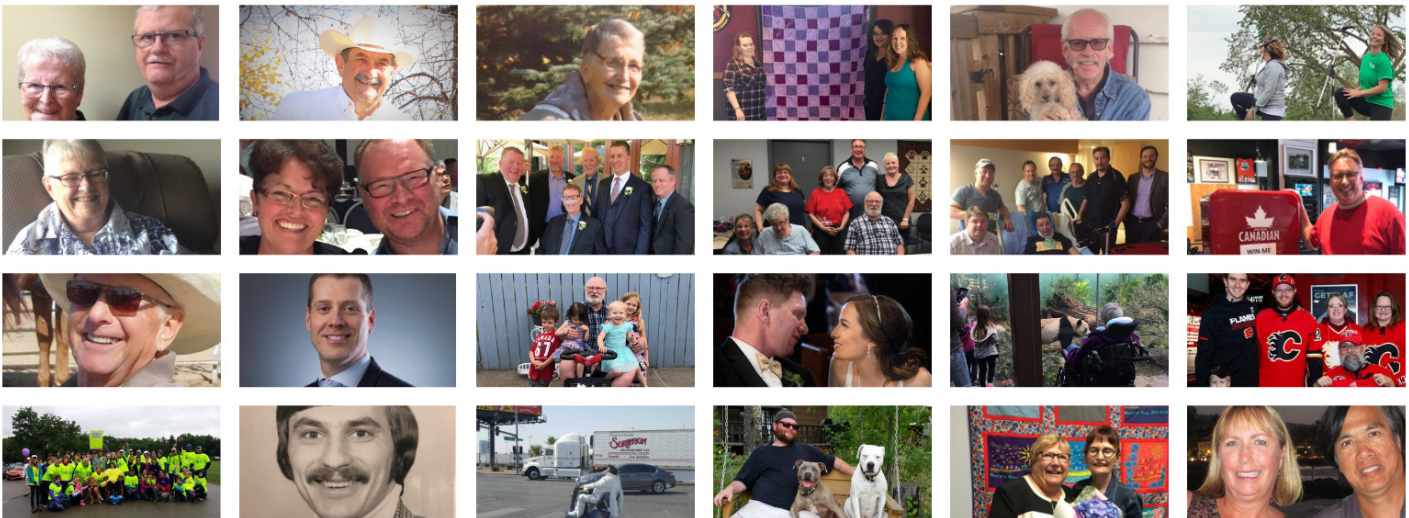
The Society expanded its connections on social media by sparking large-scale conversations about research, policy and fundraising updates. Coverage of the Society's fundraising events spanned newspapers, magazines, blogs, community calendars and more as volunteers shared their messages with storytellers in their communities. Our social media reach continues to grow as we gain more followers on Instagram, Facebook and Twitter. Since 2017, the Society's Facebook page saw an increase in likes of 16%, Twitter followers have increased by 22% and Instagram followers have increased by an outstanding 49%.



“Me and my family were blessed to go to one of these games and meet Mikael. Such a great guy and the work he and Frida are doing to fight this disease is incredible. Thank you again Mikael we are still talking about that game.”
-Rocky Leer

Making it possible

“Making it Possible” represents the ALS Society of Alberta’s mission to make each day the best possible day for those living with and affected by ALS. Each year, during the month of June (ALS Awareness Month) the Society encourages the ALS community to share stories of how they are able to make moments and memories possible with the help of their friends, families and caregivers. In 2018, we collected 25 “Making it Possible” stories from across the province and shared on the Society’s social media.



Management and volunteers

On November 8, the ALS community gathered to celebrate and thank the incredible achievements of volunteers and staff. The celebrations took place in Calgary and Edmonton where the Society presented the annual ALS Society of Alberta provincial awards. Awards were granted for exceptional fundraising, planning of the Walks for ALS, public awareness, and volunteerism. Congratulations to the recipients of the 2018 Volunteer Awards.

Norman Pollock – Exceptional Volunteer Award



Jody Round



Jean Ramsey

Exceptional Fundraising Program



Jim Robinson
Big Drew's Big Ride



O'Connor Family
PJ Impact

Walk for ALS Award



Drayton Valley



Fort McMurray

Proud Supporter



Sean MacDonald



Allan Jones & Andrew Smith

Exceptional Public Awareness Program Award



Danny Getzlaf

Long Term Service Award



Cathy Martin - 15 years

Leader of Tomorrow



Payton Moro

Making Possibilities



Glen Jarbeau

Research



2018 Research contribution

The ALS Society of Alberta is proud to be one of the largest contributors to the National Research Program in Canada.

The Society was proud to be able to contribute \$371,143 to be invested in the most promising research initiatives in Canada. This contribution is made possible by everyone who participates in the WALK for ALS and Betty's Run for ALS.

These contributions continue to make groundbreaking ALS research possible.

November 2018 was the announcement of eight exciting new research projects being funded with an investment of \$1 million through the National Research Program. These eight new research projects include multiple studies using cutting-edge techniques, never before applied to ALS, further examination of newly discovered proteins that may be critical to understanding how ALS works in the body, the use of specialized models of ALS to better understand how the disease occurs, a new spin on targeting abnormal immune and inflammatory mechanisms to treat ALS, and development of a unique Canadian protocol to measure the value of therapies on quality of life alongside medical evaluation in clinical trials.

The research being funded will seek to answer questions that will enable the exploration on new therapeutic targets, extend existing research to support further discoveries and help researchers gain a greater understanding about why ALS progresses differently in each individual.

Along with the announcement of the eight new research projects, six trainee grants were awarded that will help create Canada's next generation of ALS researchers. The funds for the trainee grants were awarded in partnership with Brain Canada.

In October, Health Canada announced their approval of Radicava (edaravone) for the treatment of ALS. This approval of edaravone is an important and hopeful milestone for the ALS community. Edaravone is only the second ALS therapy to be approved by Health Canada and the first in nearly 20 years. We hope this approval will build momentum for the development of additional therapies, underscoring the importance of research investment.



\$1.7 million
invested in Canadian ALS
research in 2018



180
researchers in attendance
at the 14th annual
Canadian research forum



8
research projects
funded

Research Forums

The ALS Society of Alberta hosted research forums in Calgary and Edmonton. Dr. Lawrence Korngut and Dr. Sanjay Kalra provided updates on new research initiatives and clinical trials.

The forums were well attended and provided a great opportunity to “ask the researcher.”



Treasurer's report



Once again the staff and volunteers at the ALS Society of Alberta have delivered on our mandate of making each day the best possible day for people living with and affected by ALS. With stories everywhere focusing on increasing intolerance towards our fellow human beings, particularly those who are challenged by circumstances, it is so very heartening to hear the daily stories of support and caring coming from the Society.

The biggest focus from the Society has always been direct client support, however we remain one of the largest contributors in Canada to ALS research. We recognize the vital importance of dealing with daily issues, in addition to looking for long term answers.

For any not-for-profit organization, the administration must steer a careful line between deficits and surpluses. Deficits that are too large or too frequent eat into the long-term sustainability of the organization and put the mission at risk. On the other hand surpluses that are too large or too frequent demonstrate that the organization could be, and should be, putting many more resources into helping its clients. This, also, does not serve the mission properly.

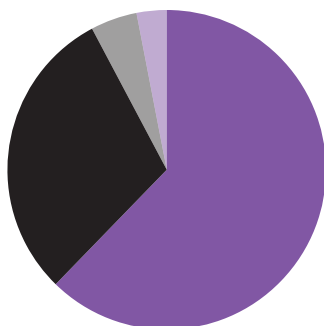
With a very small deficit in 2018 I think the Society is right on target. Revenues were over \$2.85 million and expenses just under \$2.9 million, so we finished the year with a deficit of \$24 thousand.

Through careful stewardship from the staff, the Society continues to be financially sound.

In addition to the unrestricted net surplus, the Society has internally restricted a further \$920 thousand of accumulated surplus. The administration has determined that such an amount will translate to at least 6 months of operating expenses. This prudent safety net assures all of us that the Society can continue to fully operate in the (extremely unlikely) event that all donations dry up.

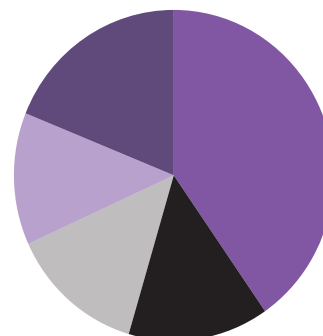
With the recent change in government it is too early to see if there will be any changes to provincial governmental involvement in this area. However the history of all governments across all jurisdictions in Canada indicate that we must continue to fill the gap. As always, the ALS Society of Alberta will continue to do so without government funding.

Gord Banting, CPA, CMA



2018 ALS SOCIETY OF ALBERTA REVENUE - \$2,843,400

Fundraising (Betty's Run, WALK for ALS, etc.)	62.28%
Donations	29.94%
Amortization of deferred contribution	4.73%
Other	3.05%



2018 ALS SOCIETY OF ALBERTA EXPENSES - \$2,881,205

Equipment and client services	40.33%
Administration	14.22%
Amortization	13.65%
Research	12.92%
Fundraising and awareness	18.88%

Community Partners

Many of the companies the Society works with find ways to give back to the community.

Thank you to F12, our IT company, for making their annual donation to the Society.



Thank you!

to our families, donors, volunteers, event organizers and event participants.

Your support is an inspiration to us all. Together we can achieve our mission and channel hope for a future without this devastating disease.





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