



2019 Annual Report

ALS Society of Alberta







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

Honouring Dave Williams

August 25, 1939 - January 28, 2019

We said goodbye to long-time board member and good friend of the ALS Society of Alberta, Dave Williams.

Dave was an active member of our Board of Directors for 12 years, from 2007 to 2019. He joined the Board following his own ALS diagnosis, wanting to raise awareness and make the lives of those touched by this disease more manageable. He led the Society during the most significant growth of our organization, with wisdom, expertise and compassion. One of his many achievements was the awareness he brought to the Alberta Government about the ALS cause, bringing the voice from a family perspective to all levels of Government including Ministers from various portfolios.

We are honoured that Dave dedicated his time and energy in making a difference in the lives of people living with ALS and their families. The impact Dave has had on the ALS Community, on our society and all of us who knew Dave is impossible to overstate. He touched thousands of people without even realizing the significance of his contributions, the depth in which he touched others and the difference he made. He will forever be remembered.



A message from the Board Chair and Executive Director

Inspiring Care, Hope and Community

Year after year, thousands of dedicated Albertans from across the province rally together to support families affected by ALS. We hear amazing stories of resilience, hope and community. Most importantly, people want to make a difference.

We dedicated June as ALS Awareness month to share the incredible stories from the ALS community across Alberta. Our families and friends shared with us inspiring stories of hope, strength and the unrelentless drive to find a cure.

It is because of the generous support of our families, and of the volunteers that give of your precious time, that we can meet our mission without local or provincial government funding. In 2019, your support allowed us to provide much needed equipment from our loan pool and dedicated client services support, all at no cost to our families.

Even in trying economic times, the ALS Society of Alberta continues to be one of the largest funders per capita of national ALS research. It is the dedication of our families to continue to collectively advocate for access to new therapies, a greater investment in research and clinical trials that is making an impact nationally.

We greatly value our partnerships with the ALS Clinics, healthcare community, home care supports and provincial societies. 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 Pentney
Chair, Board of Directors

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



Karen Caughey
Executive Director

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



BOARD OF DIRECTORS

Tara Pentney
Chair

Nancy Lyzaniwski
Vice-Chair

Gord Banting
Treasurer

Jim Robinson
Secretary

Heather Haddow
Director

Kimberly Howard
Director

Cathy Martin
Director

Karen Caughey
Executive Director

A message from the Honourary Chair



It is my honour and privilege as the Honourary Chair of the ALS Society of Alberta, to share with you the accomplishments and strides made by the Society in 2019.

Alberta hosted ten Walks to End ALS across the province in 2019, raising over \$500,000. In addition, the 23rd annual Betty's Run for ALS in Calgary raised an additional \$400,000 for ALS research and client service. These events are mainstays of the Society and mean so much to all of our families and members of our community, while raising funds for both client support, and groundbreaking ALS research.

Our dedicated friends also hosted independent events across the province, bringing their enthusiasm and energy to a wide variety of fundraisers. The ingenuity of these events impresses me year after year, as I see friends and family come together to raise awareness about ALS in their towns and cities. Despite the economic challenges faced by our province, the support we continue to receive from our families, friends, donors and sponsors is remarkable and unwavering.

Our Client Service and Equipment Loan Programs supported 442 clients across the province in 2019, providing over 1600 pieces of equipment. I am proud that our team continues to be such a support system for families across the province, as we truly make a difference in our clients' lives.

ALS research across the country continues to make advances, and I am proud that Alberta remains one of the biggest supporters of the national research program.

I am honored to continue to be a part of this society, and see it fulfil 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.

2019 by the numbers

442

Clients supported



1,651

Pieces of equipment provided



1,413

Home visits conducted



97

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



44

Community events held across the province



50

Families supported through Support for Champions



10

Walks to End ALS held in Alberta



22

Educational presentations given



100%

of requests for support fulfilled



Programs and services

In 2019, the ALS Society of Alberta continued to work to make each day the best possible day for our families through our essential services, the Client Services and Equipment Loan Programs.

Recognizing the immense importance of caregivers to the ALS community, the ALS Society hosted the first ever Caregiver's Lunch in Calgary in November. Peter and Riley Tsoulamanis of Tops Pizza South hosted the event, with Bartier Bros Wine supplying gift bottles and Paint It! providing an activity for everyone to have some fun with.

In addition, in 2019 we held presentations on ALS across the province to provide information to allied healthcare professionals. These sessions help Alberta healthcare professionals learn about the disease, its symptoms, stages and options for medical assistance.

Our Support for Champions program assisted 50 families in 2019, supporting 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 such as camps, theatre, sports and music programs.

Every year the Society conducts a client survey to identify strengths as well as areas that we can improve upon. Survey respondents identified support and coffee groups, the Equipment Loan Program and home visits as the services that were the most beneficial. 81 per cent of respondents were very satisfied with the Client Service that they received, while 80 per cent were very satisfied with the service and cleanliness of our Equipment Loan Program. We have also received the feedback that our print and online communications can be improved, and we are working hard on those aspects to ensure they are more frequently updated going forward.



Governance and advocacy

The ALS Society of Alberta's Board of Directors is comprised of volunteers that dedicate their time and expertise to lead and govern the Society. They dedicate countless hours to ensure our mission, "To make each day the best possible day for people living with and affected by ALS" is fulfilled.

The board held their annual planning session in October to reaffirm our mission and develop a plan for sustainability. The board reviewed the results of the donor survey completed in the fall to help us better understand what we are doing well, areas of opportunity and key insights so we can better plan for the future. Our donors told us to be bold, strategic and targeted in our fundraising efforts. Also, to ensure we continue to dedicate our funds first and foremost to support our clients and their families in the future.

We continue to partner with organizations to bring forward issues that impact our families. 351 families from Alberta submitted a letter to the Federal Government supporting access to Radicava. This is only the second drug therapy approved in 20 years for people living with ALS. It is the voice of the community that makes change happen. We have also partnered with coalitions and organized groups to advocate on issues that impact our families.

Resource development

Betty's Run for ALS

The 23rd annual Betty's Run for ALS took place on Sunday, June 9 at North Glenmore Park, and welcomed over 1000 enthusiastic walkers and runners. Over the past 23 years, Betty's Run has raised over \$7.8 million for client support services and research, and every year aims to celebrate, promote and channel hope to those affected with ALS, along with their families and friends. This year was no exception, and the feeling of community and hope was evident throughout the day, as we raised over \$400,000.

Each year, the Betty's Run for ALS Planning Committee chooses an Ambassador to be the spokesperson for Betty's Run. The ALS Society of Alberta was proud to welcome Ken McIsaac as the 2019 Betty's Run for ALS Ambassador. Ken generously donated his time and energy to help raise awareness about ALS.

The ALS Society of Alberta would like to thank the 2019 Betty's Run for ALS Planning Committee, the generous sponsors, volunteers, donors, participants and supporters. This event continues to make a tremendous impact on the community.



\$ 964,706
raised through the
Alberta Walks to End ALS
and Betty's Run for ALS

Walk to End ALS

In 2019, the Walk for ALS was renamed the Walk to End ALS, and ten separate events were held across the province raising a total of over \$550,000. Our enthusiastic team of community coordinators led participants from across the province, bringing energy and creativity to towns and cities including: Camrose, Cold Lake, Drayton Valley, Fort McMurray, Edmonton, Hinton, Lethbridge, Peace District, Red Deer and Valley Ridge.

The Edmonton Walk to End ALS was held on Saturday, June 8 where over 1,000 people gathered in William Hawrelak park and together raised awareness and over \$300,000. Danny Getzlaf was this year's ambassador, and he brought zest and passion to his speech, visibly moving all those in attendance.

The ALS Society would like to thank the Walk Coordinators, volunteers and participants for planning and taking part in the Walks to End ALS in Camrose, Cold Lake, Drayton Valley, Fort McMurray, Edmonton, Hinton, Lethbridge, Peace District, Red Deer and Valley Ridge in 2019.



Community events

Our ALS Community in Alberta is so generous with their time, talents and fundraising efforts, and the community events running year-round are proof of just that. Across the province, 44 separate community events were held in 2019, with proceeds donated to the ALS Society of Alberta. From concerts to golf tournaments, dueling pianos to teeter totters, our community raised awareness of ALS while reminiscing, having fun, and raising money for the Society. To highlight just a few here:

The Biemens family held their 10th annual Quonset Days festival in July, with 100 per cent of the proceeds going to the ALS Society of Alberta. Quonset Days started as a tribute to Peter Biemens, who passed away in 2009 after a hard-fought battle with ALS. Over \$400,000 has been raised since 2010, with the 2019 edition featuring Aaron Goodvin, Emerson Drive and Adam Gregory, and raising over \$65,000.

The Wagenaar family held the 2nd annual Karen's Purple Shirt Party in 2019, once again gathering friends and family in Redcliffe to honour Karen Wagenaar. This year featured a 3-on-3 hockey tournament, silent auction, dinner, and a performance by John Wort Hannam, raising \$23,000 for the ALS Society.

Hosted by 2019 Edmonton Walk Ambassador Danny Getzlaf, the 2019 Oktoberfest event in Morinville brought together music, German cuisine and beer, and an auction all to raise money for the ALS Society of Alberta. The fun and high-spirited event raised almost \$10,000 for the ALS Society of Alberta. In St. Albert, the Gish Warriors of Elmer S. Gish School held numerous events and activities throughout the year, including the popular Ice Bucket Teacher Challenge, raising over \$10,000 in total.

To everyone that organized, participated in and supported fundraising events across our province in 2019, thank you so much! Your support truly makes a difference.



Public awareness

Mikael and Frida Backlund continued their outstanding and much-appreciated support of the ALS Society and our families in 2019. Since 2014, Mikael and Frida have hosted families at Calgary Flames games, with Mikael coming up post-game to meet the attendees. Frida and Mikael have also supported the Society with game-time raffles and other fundraising efforts, and are such a constant and unwavering light for Albertans living with ALS. We have been told time and time again that attending the Flames games, and meeting Mikael, are highlights in the lives of our clients.

The Society continued to increase its social media presence, with Facebook growing in followers by 14 per cent, and likes increasing by 12 per cent. Instagram has also had a marked increase, with followers jumping almost 20 per cent in the 2019 calendar year.

Media coverage for ALS and the Society was extensive in 2019, with events such as Karen's Purple Shirt Party, Quonset Days and Oktoberfest garnering local media support. Larger events such as the Walks to End ALS and Betty's Run for ALS were also featured in traditional media.



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 2019, we collected **28** “Making it Possible” stories from across the province and shared on the Society’s social media.



Volunteer and Staff Appreciation

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 Walk to End ALS, public awareness, and volunteerism. Congratulations to the recipients of the 2019 Volunteer Awards.

Norman Pollock – Exceptional Volunteer Award



Jim McLaughlin

Exceptional Fundraising Program Awards



Gish Warriors



Howard Smith Memorial Team Roping



Sylvia Tensfeldt

Walk to End ALS Award



Cheryl Feth - Canmore

Long Term Service Awards



Nancy Lyzaniwski - 5 years



Christy Reschke - 5 years



Tara Pentney - 15 years

Proud Supporter



Mike Wagner - Co-op Home Healthcare

Proud Supporter



Congdon's Aids to Daily Living

Proud Supporter



Dan Bartier - Bartier Bros.

Proud Supporter



Mechanical Contractors Association of Canada

Research



2019 Research Contribution

The ALS Society of Alberta is proud to be one of the largest contributors to the Canadian ALS Research Program, which is supported by ALS Societies across Canada to help fuel the scientific discoveries that bring hope for a future without ALS. Albertans have been very generous in dedicating time and funds to support groundbreaking research - in 2019, Albertans contributed more than \$360,000 to the national research program through Betty's Run for ALS, Walks to End ALS, Orange Theory fundraisers and other individual contributions.

In 2019, the Canadian ALS Research Program invested nearly \$1.4 million towards leading-edge and transformational ALS research. This research is critical to understanding the biological causes and progression of ALS in order to find potentially effective treatments for this terminal disease. The ALS Society of Alberta's contributions to this program support the best Canadian ALS research, accelerating the impact of discoveries and contributing to the development of future ALS therapies.

Of the \$1.4 million invested in ALS research in 2019, more than \$850,000 was invested in ten Project Grants aimed at providing a greater understanding of biological mechanisms underlying the onset and progression of ALS. In addition, \$540,000 was invested in six Trainee Awards that will provide momentum for the next generation of promising ALS researchers. The projects funded will answer questions that will help to accelerate research discovery contributing to the development of potential ALS therapies and create a future without the disease.

The funding of the 16 research projects followed a competitive peer-review process, which engaged global ALS experts to identify projects grounded in scientific excellence and with the potential to most quickly advance the field of ALS research. The peer review was observed by people who have personal experience with ALS. To find further information on each project please visit <https://www.als.ca/research/als-canada-research-program/projects-funded/projects-funded-2019/>.



1.4 million
invested in Canadian ALS
research in 2019



200+
researchers in attendance
at the 15th annual ALS
Canada Research Forum



16
research projects
funded

Access to therapies

Leading up to the federal election, more than 2,300 Canadians sent letters to Canada's federal party leaders, asking them to create a future with equitable, timely and affordable access to proven ALS treatments.

200 + Canadian ALS researchers and clinicians attended two days of scientific presentations at the ALS Canada Research Forum, sharing knowledge and identifying collaborations for future research initiatives.

More than 100 people participated in webinars to start mobilizing advocacy efforts for provincial drug plans to reimburse Radicava.

Treasurer's report



Thanks to our strong community of staff, volunteers, donors and families, in 2019 the Society continued to deliver on its mandate of making each day the best possible day for people living with and affected by ALS, without any government funding supports or costs to our clients.

Betty's Run for ALS in Calgary and the Walks to End ALS across Alberta were once again huge successes in 2019, raising almost one million dollars combined. Our friends and families also continued to raise awareness and funds for ALS in their communities, hosting a wide variety of events in numerous towns and cities across the province.

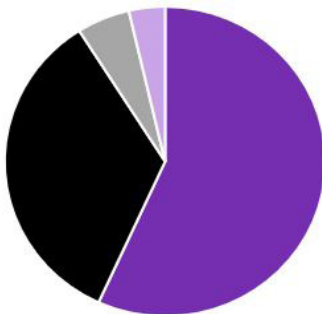
At the end of 2019, the Society retained a healthy liquidity with its cash and short-term investments at \$3,013,342. Operational revenue was \$2.2 million and operational expenses were \$2.6 million, leaving the Society with a small profit of \$5K after other income and expenses.

In prior years, the Board established both restricted and unrestricted funds to be used to offset budget deficits in years where fundraising and donation revenue declined due to economic conditions. While this annual report summarizes the 2019 calendar year, I feel that due to the current conditions, I should also take a brief look ahead to the future.

Like all other charities and non-profits, a pandemic was not part of the budget planning for the coming 2020 year; therefore, the Board is closely monitoring the impact of the pandemic on the organization. The Society continues to change and adapt to conditions related to COVID-19, and is providing the same high level of services to our clients throughout this period. I am so proud of the changes our team has made to ensure that our clients and families still receive the support that they need.

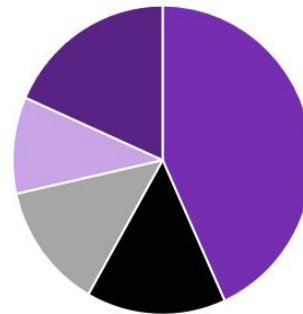
2020 will certainly be a challenging year around the globe, and we are thankful that strong years of fundraising and balanced budgets mean we have reserve funds to aid with continuity in these uncertain times.

Gord Banting, CPA, CMA



2019 ALS SOCIETY OF ALBERTA REVENUE

- Fundraising (Betty's Run, WALK for ALS, etc.) 57%
- Donations 34%
- Amortization of deferred contribution 5%
- Other 4%



2019 ALS SOCIETY OF ALBERTA EXPENSES

- Equipment and client services 43%
- Administration 15%
- Amortization 13%
- Research 10%
- Fundraising and awareness 18%

Community Partners

Many of the companies the Society works with are also very philanthropic and find ways to give back to the community.

Thank you to F12, our IT company, and Mawer Investment Management Ltd. for your donations in 2019!

MAWER

Be Boring. Make Money.™



Consider **IT** done.

A close-up photograph of a purple flower, possibly a pansy, with numerous clear water droplets on its petals. The background is a soft, out-of-focus purple and white. The text "Thank you!" is overlaid in a large, bold, purple font.

Thank you!

to each and every donor, volunteer, event organizer 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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FUNDRAISER FOR THE ALS SOCIETY OF ALBERTA

JOHN WORT HANNAM / T. BUCKLEY
EMILY TRIGGS / MIKE STACK
JESSE DOLLIMONT / RANDALL WIEBE
and the House Band Extraordinaire!

SEP. 26th, 2019 EMPRESS THEATRE - FORT MACLEOD
SEP. 27th, 2019 FISH CREEK CONCERTS - CALGARY

LIVE HOUSE BAND





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