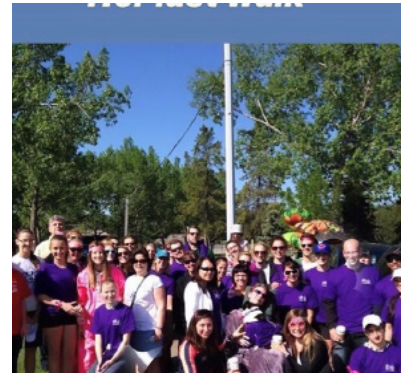


2020 Annual Report

The ALS Society of Alberta





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



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Message from the Board Chair and Executive Director



Karen Caughey
Executive Director

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



Nancy Lyzaniwski
Chair, Board of Directors

A handwritten signature in black ink that reads "Nancy Lyzaniwski".



2020 was a year the world will never forget. At the start of the pandemic, the Board of Directors strategically made governance shifts to ensure Board policies were not unintentionally creating obstacles for the staff to continue to provide supports to our families. The team quickly navigated through ever-changing restrictions and so many unknowns about Covid-19 while focusing on keeping our families and team safe. The work of the Client Services Team evolved into an opportunity to maximize technology that welcomed interaction with clients across the province. Our annual Walk to End ALS, Betty's Run for ALS and summer events morphed into an opportunity for smaller, creative, and inclusive events across the province that were shared online.

Our Board set the foundation for opportunity. An opportunity for inclusion – for our already very engaged community to interact through technology as never before. An opportunity for research – advances in treatment for one disease are often the result of research for another disease. An opportunity for adaptation – for our staff to continue to be flexible in changing the way they work to meet restrictions to keep themselves and our families safe. An opportunity for collaboration – to share and learn from other non-profit health service organizations. An opportunity for fundraising innovation – to be creative in our fundraising events by doing something we've never done before.

As a charity that receives no government funding, we rely on fundraising and donations to maintain our programs and services. As such, we will continue to work hard on alternate sources of funding, such as grants, online fundraisers and other avenues. Our commitment to our mission and to the families we serve is steadfast, and we will continue our fundraising work to ensure this is maintained.

Thank you to the amazing ALS community for helping us ensure we can continue to make each day the best possible day for those living with and affected by ALS.

Board of Directors

Nancy Lyzaniwski
Chair

Tara Pentney
Past Chair

Gord Banting
Treasurer

Jim Robinson
Secretary

Heather Haddow
Director

Cathy Martin
Director

Pamela Keenan
Director

Kimberly Howard
Director

Karen Caughey
Executive Director

Message from the Honourary Chair

It is my privilege as the Honourary Chair of the ALS Society of Alberta, to share with you the accomplishments of the Society in 2020 in what has been an unprecedented and challenging year for us all. This year more than ever, I am inspired by the work of the Society and its dedication to supporting those living with and affected by ALS.



In the early days of the pandemic, the Society and its team of staff and volunteer committee members chose to adapt all 2020 editions of the Walks to End ALS and Betty's Run for ALS into a virtual event. The quick pivot required ingenuity and adaptability, which came through in spades. Between Betty's Run for ALS and the Walks to End ALS, all held on June 21st, our generous and consistent supporters helped us raise over \$530,000 to support Albertans living with ALS and ALS research. I am very proud of this amazing accomplishment during such difficult circumstances.

Our Client Service and Equipment Loan Programs maintained full services during the pandemic, with our Client Service team reaching out to all our families and ensuring they remained supported. Visits moved to virtual formats, and our team engaged with our clients and families 5812 times in 2020 via phone, text and Zoom. Support groups actually grew in 2020, with clients, families and caregivers logging in via Zoom and making connections across the province. In addition, our Equipment Loan Program provided equipment to clients across Alberta, using new vendors as needed for socially distanced delivery. The rapidly changing needs of those living with ALS require consistent and ongoing support, and I am so very proud that our team persevered through COVID-19 to ensure our clients remained safe and supported.

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

I am honoured 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

Covid-19 Impact

In the early days of the pandemic, the ALS Society of Alberta worked hard to quickly understand how the pandemic, and the associated restrictions in place, would affect our families. We were able to stay open after being deemed an essential service to our ALS clients with our Equipment Loan program and support groups. We shifted our support services to a virtual model and connected with our families so they knew we were still here for them. Throughout the pandemic, we never stopped our services, or our focus on our mission.

Support Groups

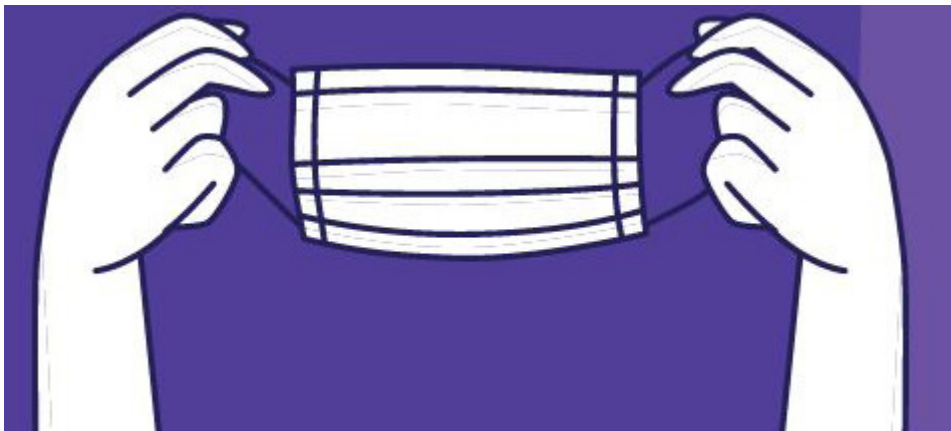
With the government restrictions on in-person gatherings due to COVID-19, the ALS Society of Alberta quickly shifted all support groups to an online/virtual format. An unexpected benefit of this change was that suddenly, individuals from all corners of the province could meet up and support each other. The sense of community and friendships made through these groups have been so important during the pandemic. In 2020, 106 virtual support groups were hosted by the ALS Society of Alberta.

Family Engagement

Our dedicated client service team worked hard in 2020 to ensure that every client and family knew that we were still here to support them. In fact, our team had **5812** telephone, text message and email engagements with our families over the year, as we supported over **400** families living with ALS. We worked hard to ensure people were able to live safely in their homes, coordinating with vendor partners to ensure equipment was still delivered even with physical distancing requirements.

Events

With our major events scheduled for June of 2020, quick decisions were made to switch all in-person Walks to End ALS and Betty's Run for ALS to a large, Alberta-wide virtual event on June 21st. Our community came together virtually, sharing photos, videos and stories online throughout the day. Thanks to our sponsors, donors and participants that made it all possible!



2020 by the numbers



412
families
supported

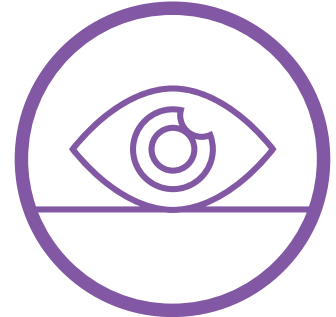


1736
pieces of
equipment
on loan

106
virtual
support group
sessions



5812
Client
Check-Ins



11
community
events
in Alberta



11
Walks and
Betty's Run
for ALS

100%
of requests
for support
fulfilled



Governance and Advocacy

Six months into the pandemic we held our annual board planning sessions and fortuitously, the bi-annual board/staff planning day. These discussions were beneficial in that staff and Board members had an opportunity to participate in scenario planning, a process where we challenged each other's assumptions, explored issues, and brainstormed the possible scenarios our organization could face in the future.

The ALS Society of Alberta's Board of Directors is comprised of passionate volunteers that dedicate their time and expertise to lead and govern the Society. In 2020, the board was challenged with ensuring our mission, "To make each day the best possible day for people living with and affected by ALS" was fulfilled in the ever-changing environment caused by the pandemic. The board met immediately when the pandemic was declared and planned for the year to support the staff team, ensuring our programs were not interrupted but delivered safely. In the fall, the board moved forward with their annual planning session with the staff to explore the impacts of an uncertain and evolving external environment and what strategic implications this might have for the organization.

This past year tested the strength of the ALS Community. Our families, volunteers and staff team showed resilience and together we never wavered from our mission.

We continue to partner with the provincial health coalition and national groups to advocate on issues that affect Albertans living with ALS. The first drug for ALS in 20 years was approved by Health Canada in 2019. We continued to advocate for the drug to be added to the provincial drug plan in Alberta to ensure people eligible for the drug would have access. On June 1, 2020, Radicava was added to the Alberta Drug Benefit List formulary. Albertans affected by ALS are leaders in influencing positive changes. It is the voice of the community that makes change happen.



Resource Development

Betty's Run for ALS

The 24th Annual Betty's Run for ALS was one like no other before it, due to the COVID-19 pandemic and the inability to hold an in-person event. The Betty's Run Committee quickly decided to adopt a virtual event and worked with the ALS Society to implement all aspects of the new format.

Over the past 24 years, over 8 million dollars has been raised via Betty's Run for client support services and research, while celebrating hope, care and community. Unfortunately, COVID-19 eliminated the opportunity to be together in person, but our community came together online and brought so much hope and energy, even from a distance. Our over 450 registrants, including 59 teams, raised over \$264,000 amid the pandemic.

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 Katherine Gartner as the 2020 Betty's Run for ALS Ambassador. While not a normal year for our Ambassador, Katherine generously donated her time in media interviews to help raise awareness about ALS.

The ALS Society of Alberta would like to thank the 2020 Betty's Run for ALS Planning Committee, the generous sponsors, volunteers, donors, participants and supporters. This event, especially in 2020, made a tremendous impact on the community.

Walk to End ALS

In 2020, the Walk to End ALS also forged ahead during COVID-19, switching to a virtual format and bringing all the walks together online on ALS Awareness Day - June 21st. Participating communities in 2020 were: Camrose, Cold Lake, Drayton Valley, Edmonton, Fort McMurray, Grande Prairie, Hinton, Lethbridge, Peace District, and Red Deer. Over 270 individuals from across the province registered and fundraised as part of the Walks, raising over \$275,000. The Society was honoured to welcome Gail Rauw as the 2020 Ambassador for the Edmonton Walk to End ALS.

The ALS Society of Alberta would like to thank the Walk Coordinators, participants, sponsors and donors for their amazing support in 2020.



Community Events



In 2020, Community Events were unfortunately hit hard by the COVID-19 pandemic. Our always generous and supportive community, that in most years holds dozens of fundraising events in communities across the province, was forced to cancel plans due to provincial restrictions. However, our always ingenious supporters still came through with new and different ways to raise funds on our behalf. Here are just a few of the community events that happened in early 2020, and in creative ways the remainder of the year.



The Purple Shirt Party continued its support of the ALS Society of Alberta on Feb. 28th, when Medicine Hat High School transformed from green to purple as the basketball teams held their 2nd event in honour of Karen Wagenaar and the Karen's Purple Shirt Party initiative. In the lead-up to the games, the teams also brought back the Ice Bucket Challenge, and shirts were sold at the game with all proceeds (over \$3000) going to the ALS Society.

Altario School Students raised \$10,000 in honour of their teacher that lived with ALS, Mrs. Kari Evans, who sadly passed away in November 2020. They raised funds with a silent auction, Christmas dinner, and donations from the community. Altario school also raised \$1500 with an ice bucket challenge on April 7th! In March, the **MCG Simmentals and Rack Red Angus Bull Sale** took place in Stavely, AB. In honour of Judy, and in gratitude for the support provided by the ALS Society over the years, the Brown family auctioned off one of Judy's beautiful handmade quilts at the start of the auction. Over \$11,000 was raised for the ALS Society of Alberta through both the auction and additional donations. Finally, **Wayne Thomas** released his book "**Perspectives**" in 2020, which documents his journey with ALS. 70 per cent of the proceeds of his book sales go to the ALS Society of Alberta.

To everyone that organized, participated in and supported fundraising events across our province in 2020, thank you so much! Your support truly makes a difference.

Grants and Foundations

The ALS Society of Alberta was proactive in searching out new sources of funding in 2020, as our events were altered or canceled and we researched supplemental resources via grants and foundations. We are thankful for the foundations that supported us in 2020, including the Nickle Family Foundation and the Community Foundation of Lethbridge and Southwestern Alberta.

The Community Foundation of Lethbridge and Southwestern Alberta provided the ALS Society of Alberta with a \$10,000 grant to purchase equipment for the Equipment Loan Program. Specifically, this grant assisted in the purchase of stair lifts and cough assist machines for our clients in Southwestern Alberta. The Nickle Family Foundation also confirmed a donation in December 2020. Their gift of \$10,000 is a one-time grant in support of our Equipment Loan Program, and both grants are so very much appreciated by the Society and the families we support.



Public Awareness

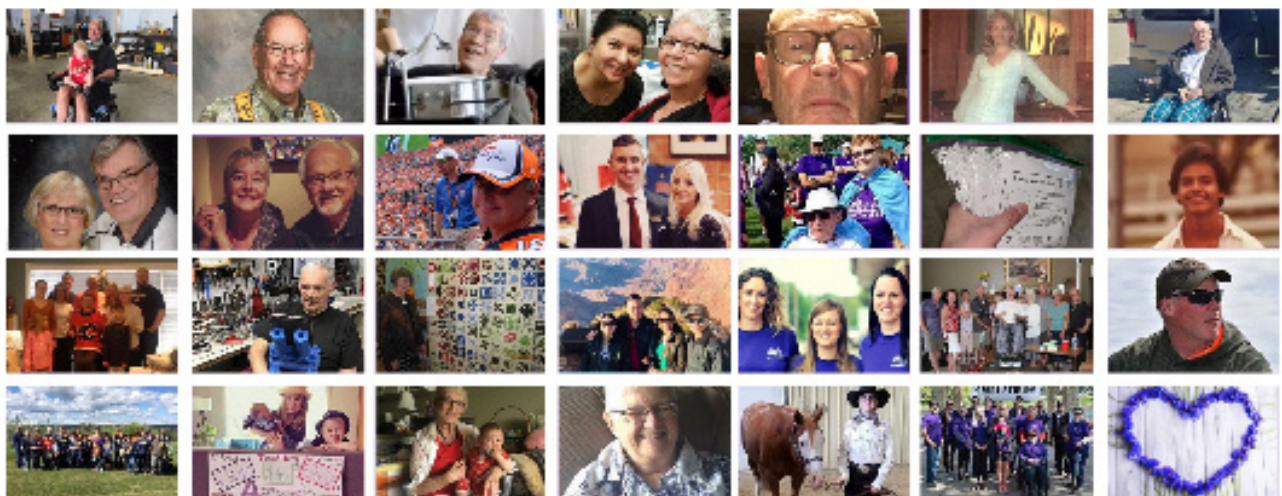
Mikael and Frida Backlund continued their outstanding and much-appreciated support of the ALS Society and our families in 2020, both before and during the pandemic. Since 2014, Mikael and Frida have hosted families at Calgary Flames games, with Mikael coming up post-game to meet the attendees. This continued until in-person games were cancelled in March of 2020. Mikael, however, continued to support our families in 2020 by hosting meet and greets on Zoom with members of our community. In addition, Mikael continued his financial support, and for the 2020/21 season donated \$500 for every goal scored, matched with \$250 donations from both the Flames Foundation and KPMG. Frida Backlund and the Flames Wives also supported us with a raffle in early 2020, and we are forever thankful for the Backlunds' unwavering support.

The Society continued to increase its social media presence, with Facebook followers and likes growing by 10 per cent. Our Instagram followers increased dramatically in 2020, going up by over 40 per cent. This was in large part due to the additional content during Betty's Run and the Walks to End ALS, and the support of Calgary sponsor Curiosity.



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 2020, we collected 27 “Making it Possible” stories from across the province and shared on the Society’s social media pages.

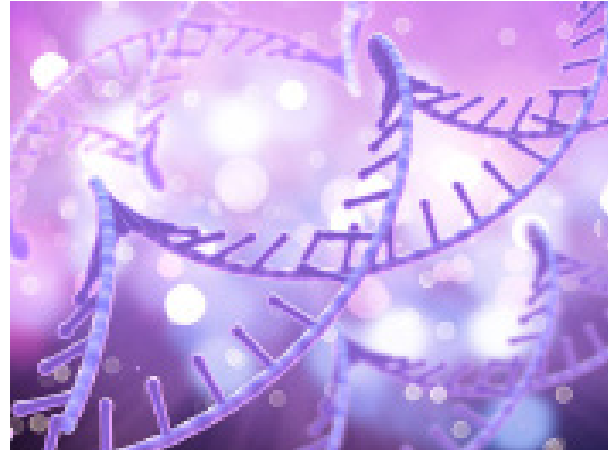


Research

The ALS Society of Alberta was proud to continue its support of ALS national research in 2020. Even during this pandemic year, with reduced resources, we contributed \$153,000 to be invested in the most promising research initiatives in Canada. **This contribution is made possible by everyone who participates in and donates to Betty's Run for ALS and the Walks to End ALS.**

The National Research Program awarded eight discovery grants in 2020 to pursue innovative new areas of ALS research including genetics, biomarkers, pathways for future therapies, and quality of life.

Two Alberta Doctors were awarded Research Fellowships in 2020 as part of the national program that we support. Dr. Colin Luk at the University of Alberta was awarded the ALS Canada Clinical Research Fellowship, while Dr. Gordon Jewett of the University of Calgary was awarded the Mitsubishi Tanabe Pharma Canada Fellowship.



Programs and Services

In 2020, the ALS Society of Alberta worked tirelessly through the Pandemic in order to continue making each day the best possible day for our families through our essential services: the Client Services and Equipment Loan Programs. Both programs were affected by COVID-19, but our team pivoted to find solutions to these new challenges. Support groups went online, welcoming even more people who could now join from smaller communities. Equipment was still delivered, while ensuring social distance and sanitization protocols were enforced. Our team of client service coordinators managed 5812 check-ins with clients over the year, even if in-person visits were not possible.

Treasurer's Report

What a year! Staff, volunteers and clients adjusted very well to new contact requirements arising from the pandemic. It made a difference on our fundraising revenue, as you might well imagine (42% of total compared to 57% last year); however, I want to thank all the wonderful participants for their imaginative approaches. Even with the drop it was still a very significant amount (over \$800K). A new and important source of revenue for the year (but we hope not necessary to continue) was the rental and salary support from the federal government. In-person visits had to cease, but staff were able to come up with workarounds; Equipment and Client Service cost actually increased as a percentage of total expenses, to 48% from 43%.

We sincerely hope that the light we see is not another train coming at us, but staff are already planning how to move forward with more events and activities for the future. We have shown the Society can adapt to whatever comes our way.

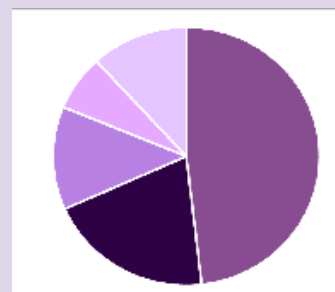
When the shutdown hit, management and the board took another look at our budget and felt that the impact on fundraising would be dramatic. However, we did not want to compromise our mission – to make each day the best possible day for those living with and affected by ALS. All changes to services were driven by health concerns and none by financial concerns. We were prepared to sustain a significant deficit in the year, and comfortable that our strong financial position gave us runway to weather several years without having to impact services to our clients. We still have that understanding.

At the end of 2020, the Society realized a small annual surplus of \$95K, with revenue just shy of \$2.3M and operating expenses not quite \$2.2M. Strong stewardship and creative approaches overcame what actually could have been a deficit. We still have a healthy liquidity with cash and short-term investments at \$3.3M.

2021 will have its uncertainties, but more clarity is coming almost daily. And it is looking very positive for the Society. Already, revenue is above expectation. Staff continue to show their flexibility and creativity in providing services. The patience shown by clients, and the understanding from staff, have allowed management and the board to look to the future with confidence.

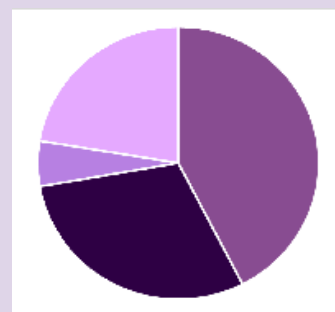


Gord Banting, CPA, CMA



2020 ALS Society of Alberta Expenses

Equipment and Client Services	\$1,052,356	48%
Administration	\$439,783	20%
Amortization	\$282,576	13%
Research	\$152,223	7%
Fundraising and Awareness	\$257,790	12%
Total:	\$ 2,184,728	



2020 ALS Society of Alberta Revenue

Fundraising	\$839,456	42%
Donations	\$589,577	30%
Amortization of deferred contributions	\$105,985	5%
Other	\$443,207	22%
Total:	\$ 1,978,225	

THANK YOU!





The ALS Society of Alberta



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