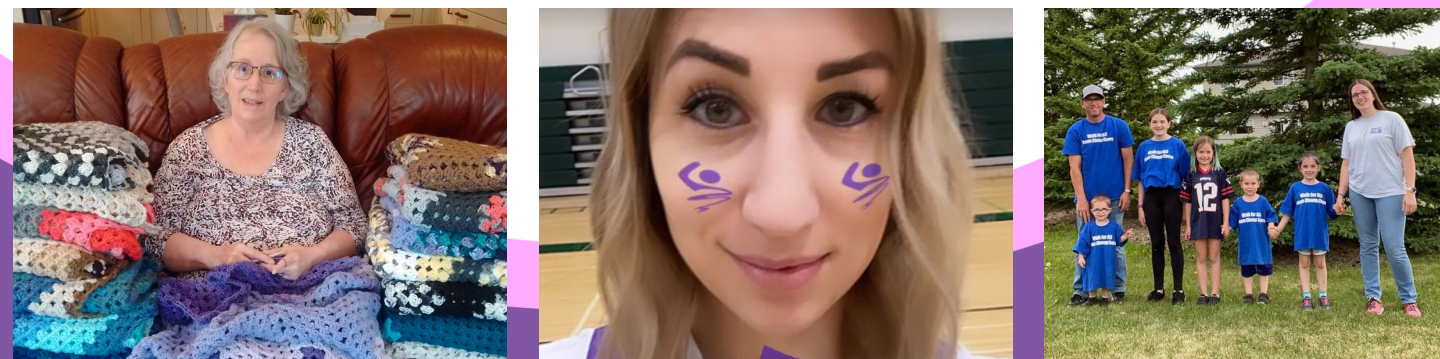


2021 Annual Report

The ALS Society of Alberta





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



Contents



Page 2 Message from the Board Chair and Executive Director	Page 7 Resource Development
Page 3 Message from the Honourary Chair	Page 8 Community Events Grants and Foundations
Page 4 Programs and Services	Page 9 Public Awareness Making it Possible
Page 5 2021 by the numbers	Page 10 Research
Page 6 Governance and Advocacy	Page 11 Treasurer's Report



Message from the Board Chair and Executive Director



Karen Caughey
Executive Director



Nancy Lyzaniwski
Chair, Board of Directors



Reflecting on 2021, our community continued to manage through the pandemic with incredible resilience, courage, and sheer strength. To say 2021 was a tough year is an understatement. Continuing to navigate the ever-changing Covid-19 protocols and restrictions brought uncertainty to our daily lives. Our families took on enormous challenges managing ALS with the added burden of the pandemic to make things even more difficult. We missed the face-to-face contact, but through it all, we never lost sight of our mission to make each day the best possible day for people living with ALS. We never shut our doors, continuing daily to serve our families even if restrictions required adaptations to how we worked. Our annual Walks, Betty's Run for ALS and summer events continued virtually for the second year. As we discovered, virtual events brought family and friends together from places across the country and even around the world. The community taught us resilience and incredible creativity.

The Alberta ALS community rallied to raise funds to ensure we could continue to support our families and fund critical leading-edge research. The impact of the funds we dedicated to research was broad, as they funded a fellowship, research projects, and clinical trials. We took the opportunity to continue to share and learn from other non-profit health service organizations. We shared our voice, advocating for access to new therapies, home care supports, and much-needed equipment through our provincial health program. As a charity that receives no operational funding from the Government, we rely on fundraising and donations to maintain our programs and services. The continued dedication of our community and supporters through the past two years has been imperative, and we are incredibly thankful.

Thank you to our families, donors, partners, and volunteers for making our work together a constant source of inspiration. And thank you for the efforts of our wonderful board members and staff whose deep passion, tireless dedication, and perseverance helped us live our mission.

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

Tom Gee
Director

Karen Caughey
Executive Director

Message from the Honourary Chair

In yet another year of unprecedented worldwide events, I feel privileged to share with you the accomplishments and continued dedication of the ALS Society to Alberta families in 2021.

As the Society and its staff continued to adapt to the reality of the pandemic, the Client Service team maintained its online support system and Equipment Loan program. Support groups continued to grow, welcoming ALS clients, caregivers, and family members to 113 support groups in 2021. Taking place online meant that individuals from across the province could join, and additions to our pool of ipads and improvements to some of our technology made it easier to take part. The Equipment Loan Program maintained delivery and service standards, following social distancing rules with new vendors while still providing 1561 pieces of equipment to families across the province. With the rapidly changing needs of ALS families, the ability to provide this program with urgency and accuracy is of key importance, and I am proud of the work our staff and volunteers do to make this possible.

Events in 2021 remained for the most part virtual, but our community rallied around them with enthusiasm. Both the Walks across Alberta and Betty's Run for ALS increased their fundraising totals from 2020, thanks to the support of so many not only in Alberta, but around the world. Between Betty's Run for ALS and the Walks across Alberta, our generous supporters and sponsors helped raised over \$600,000 to support Albertans living with ALS and ALS research. Despite the challenging circumstances that our families and Albertans were under, the support we continued to receive is remarkable and unwavering.

ALS research across the country continues to make advances, and I am pleased that Alberta remained 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

Programs and Services

Another year of the pandemic forced us to be flexible with changing restrictions in order to best serve our families. Our essential service status allowed us to continue providing assistance through our Equipment Loan Program and support groups. We continued our support services in 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

In light of ongoing restrictions, our support group sessions remained online for the duration of 2021. The virtual format allowed clients to join in from anywhere, which gave each session a greater sense of community. The friendships made through these groups have been so important during the pandemic, when in-person contact was limited. In 2021, **113** virtual support groups were hosted by the ALS Society of Alberta.

Family Engagement

Our client service team continued their efforts to support each and every one of our families throughout 2021. Each telephone, text message, email and video call resulted in **6812** engagements with our **443** families living with ALS.

Equipment Loan Program

The Equipment Loan Program maintained services throughout 2021, ensuring that deliveries were made quickly by our vendors while maintaining social distance requirements. **1561** pieces of equipment were on loan to our families in 2021, as our team worked to ensure that clients were able to continue living safely and comfortably in their homes.

Events

All of our events, including our multiple walk fundraisers and Betty's Run for ALS, remained virtual for the year of 2021. We may have been separated physically, but everyone came together through photos and videos to show their overwhelming support. Thanks to our sponsors, donors and participants that made it all possible!



2021 by the numbers



443
families
supported

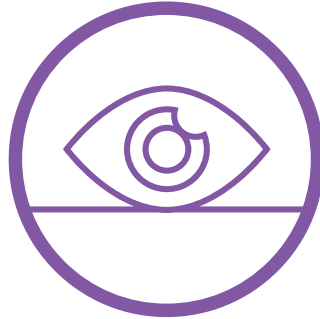


1561
pieces of
equipment
on loan

113
virtual
support group
sessions



6812
client
check-ins



13
community
events in
Alberta



12
virtual
Walks &
Betty's Run
For ALS

100%
of requests
for support
fulfilled



Governance and Advocacy

The ALS Society of Alberta's Board of Directors is a passionate group of leaders who strategically guide our organization. Each member dedicates their time and expertise to lead and govern the Society. As we continued living with the uncertainty of the pandemic, the board dedicated time and resources to ensure we could continue to meet our mission, "To make each day the best possible day for people living with and affected by ALS."

In the fall, the board dedicated the annual planning session to a strategic discussion on funding ALS research. A strong foundation to build upon the Society's dedication to ALS research was established and will be the basis of future planning. We continue to partner with the provincial health coalition and national groups to advocate for issues that affect Albertans living with ALS. Access to new treatments in a timely manner has been a priority for people living with ALS. As new treatments become available, it is critical for our provincial and federal governments to react quickly and with urgency to approve these options. Albertans are some of the most active advocates across Canada. It is the voice of the community that makes change happen.

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. Looking ahead to the other side of the pandemic, we are thankful for the board's support and guidance as we navigated the difficult times, allowing us to focus on our families.



Resource Development

Betty's Run for ALS

The 25th Annual Betty's Run for ALS was a momentous milestone highlighting the collaboration and generosity of the ALS community. Despite having to work with a virtual format once again, teams and individuals came together to raise funds and spirits for those affected by ALS.

Over the event's 25 year history, over 8.5 million dollars has been raised 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. The over 400 registrants, including 62 teams, raised over **\$375,000** 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 Pete Truch as the 2021 Betty's Run for ALS Ambassador. While not a normal year for our Ambassador, Pete generously donated his time in media interviews to help raise awareness about ALS.

The ALS Society of Alberta would like to thank the 2021 Betty's Run for ALS Planning Committee, the generous sponsors, volunteers, donors, participants and supporters. This event, especially in 2021, made a tremendous impact on the community.

Walks Across Alberta

In 2021, the Walks also pushed through the pandemic as they remained in an online format. However, all communities joined together virtually on ALS Awareness Day - June 21st, sharing photos and videos across social media platforms. Participating communities in 2021 were: Altario, Camrose, Cold Lake, Drayton Valley, Edmonton, Fort McMurray, Grande Prairie, Hinton, Lethbridge, Peace District, Wainwright and Red Deer. Over 280 individuals from across the province registered and fundraised as part of the Walks, raising over \$300,000.

The ALS Society of Alberta would like to thank the Walk Coordinators, participants, sponsors and donors for their amazing support in 2021.



Community Events



In 2021, Community Events unfortunately continued to be limited by the COVID-19 pandemic. Although our community had grown slightly more accustomed to virtual events since 2020, some opportunities simply weren't possible with the 2021 regulations.

Despite this, our supporters thought outside the box and were still able to deliver some truly special fundraising and community building moments. Here are just a few of the community events that happened in 2021.

Adam's Pale Ale was a massive initiative from Sea Change Brewery in honour of Adam Rombough who passed from ALS in 2018. Sea Change produced an incredible 17,376 tall cans of Adam's Pale Ale, with \$1 from each four pack going to the ALS Society of Alberta. This partnership resulted in over \$8000 raised for the Society.

Devil's Head Coffee also came on board as a partner in 2021, creating their "**Moments**" ALS Blend. \$2 from every bag sold went to the Society, thanks to founders Tanis and Chris Meginbir and in honour of Tanis's brother Chad Keenan who was supported by the ALS Society.

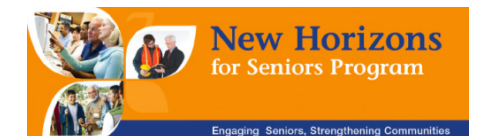
In August, the **20th Annual Howard Smith Memorial Team Roping** took place in Eagle Valley, AB. The Smith family has held this event since 2002, and with the help of their grandchildren and great grandchildren, it will continue Howard's legacy. Over 70 ropers competed for the coveted prizes and the event raised over \$6500.

Finally, the **Crash-it Golf Tournament** was a huge supporter of ours in 2021. 144 golfers came together for ALS families in Alberta, raising \$17,500 for the ALS Society of Alberta. Thank you so very much to the committee and all participants!

Grants and Foundations

The ALS Society of Alberta continued to find alternate sources of funding in 2021, as in-person events remained sidelined for the most part due to the COVID-19 pandemic. The **New Horizons for Seniors Program** provided a grant to purchase 12 ipads in 2021, which were in turn used by over 30 clients in that year alone. Access to these ipads allowed for our clients to connect to online support groups, and also stay in touch and communicate with friends and family. The Society continued to receive support from the **Edmonton Community Investment Operating Grant (CIOG)** in 2021, as they once again stepped up to help the Society maintain and improve services to clients in the Edmonton area.

The **Alberta Community Initiative's Project Grant** was also an important aspect of our funding in 2021, as it allowed us to upgrade technology required for increased telephone/online communications during the pandemic. Finally, **Source Energy** stepped forward in 2021 with a generous grant to help us continue to fulfil our mission - to make each day the best possible day for those living with and affected by ALS. The ALS Society is very grateful for the support of these agencies and companies in 2021.



Public Awareness

Mikael and Frida Backlund continued their longtime support of our families in 2021, connecting via Zoom call for the first half of 2021, and providing tickets to families when fans were once again allowed in the Saddledome in fall of 2021. The Backlunds' ongoing support continues to mean so much to the Society, but more importantly, to the families that we are so honoured to support.

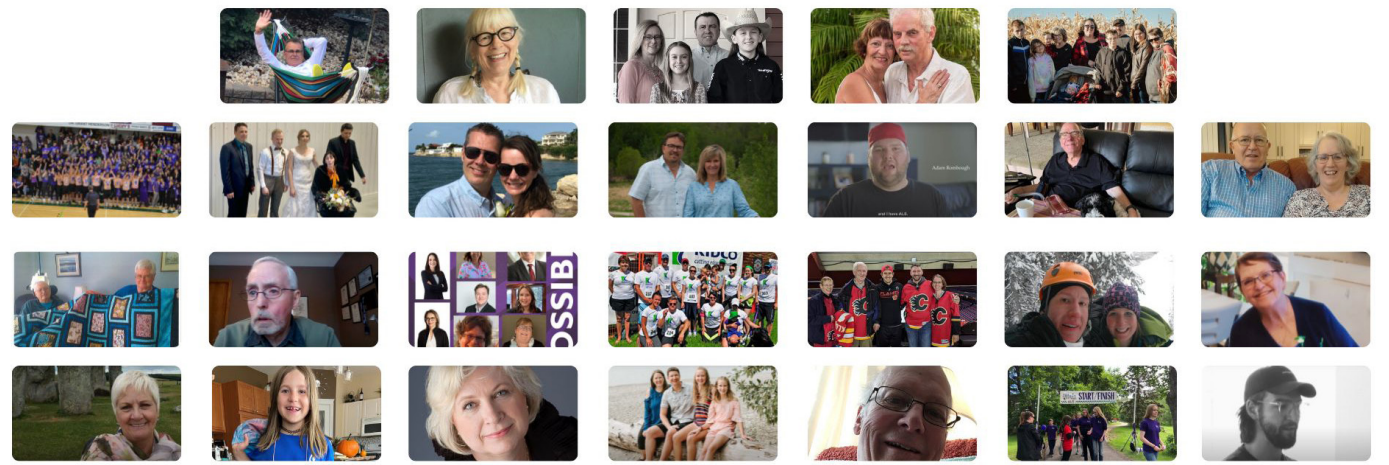
Our social media audience continued to grow in 2021, with more than 200 new individuals following our Facebook page over the course of the year. Instagram continued to grow exponentially as well, with another 40 per cent year over year growth in followers. Our increased social media presence, and connections to those with larger audiences, has meant our reach has increased substantially and we continue to focus on providing excellent content.

In 2021 the ALS Society of Alberta took notice of the popularity of 50/50 raffles in this province, and held two 50/50 cash draws. Both sold out, with the two winners each taking home \$10,000. Our raffle pages were shared widely, again increasing visits to our social media pages and website in the weeks leading up to the draws.



Making it Possible

“Making it Possible” is a spotlight on the stories of our ALS families, highlighting their journey with ALS and how the Society improves their quality of life. 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 2021, we collected 25 “Making it Possible” stories from across the province and shared on the Society’s social media pages and our website.

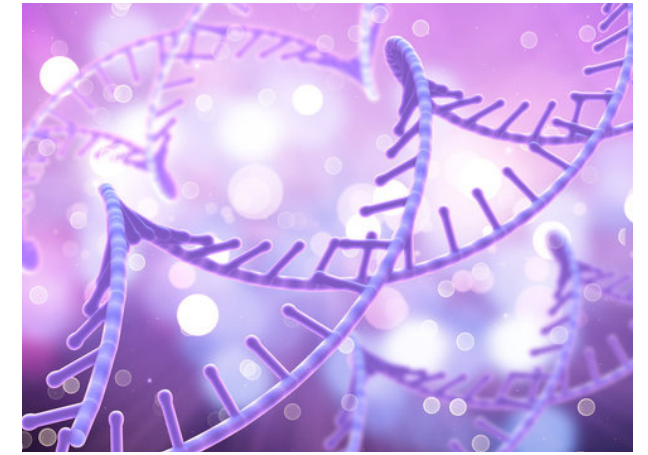


Research

The ALS Society of Alberta was proud to continue its support of ALS research in 2021. This is a time of hope in the ALS research community, as researchers work to better understand the disease and find effective treatments. Albertans have contributed more than \$8 million to research programs through the ALS Society of Alberta, thanks to participation in Betty’s Run for ALS and the Walks across Alberta.

Alberta’s world-renowned researchers are a big part of the current push for answers about ALS. Multiple clinical trials continued in both Edmonton and Calgary in 2021, often in partnership with pharmaceutical companies. Nine recipients of the ALS Canada-Brain Canada Discovery Grant competition were announced in 2021, including a clinical trial with participation at the University of Alberta with Drs Sanjay Kalra and Kevin Jones, and biomarker research also in collaboration with Dr. Kalra and Dr. Schirmacher at the University of Alberta.

CAPTURE ALS, led by Dr. Sanjay Kalra at the University of Alberta, is a research platform that provides the systems and tools necessary to collect, store and analyze vast amounts of information to create the most comprehensive biological snapshot of people living with ALS. Dr. Kalra and his team hope to identify unique subtypes of ALS, allowing for personalized care and treatment. By openly sharing this data globally, Canadians will play a major role in the global effort to understand and treat ALS. Recruitment for this project will begin in 2022.



Treasurer's Report

While 2021 brought another year of adjustments and uncertainty due to the pandemic and its restrictions, the ALS Society of Alberta and its staff, volunteers, and families continued to persevere in the face of challenges. With the ongoing changes came great resilience and renewed dedication to fundraising. Our major fundraising events revenue made up 60 per cent of total revenue this fiscal year, compared to 52 per cent in 2020.

Our Client Service team and Equipment Loan Program continued their support of our families throughout another pandemic year. In-person visits were still online, but staff were able to come up with adjustments to support clients. Equipment and Client Services costs increased slightly as a percentage of total costs from 48 per cent to 50 per cent, confirming that the needs of our families did not slow down in the face of COVID. Our support services continue to be vital in the effort to keep those living with ALS safely in their homes for as long as possible.

Revenues totaled \$2.1 million, slightly less than 2020, while total expenses in turn totaled \$2 million. The liquidity of the Society is healthy, with a total of \$3.5 million in investments.

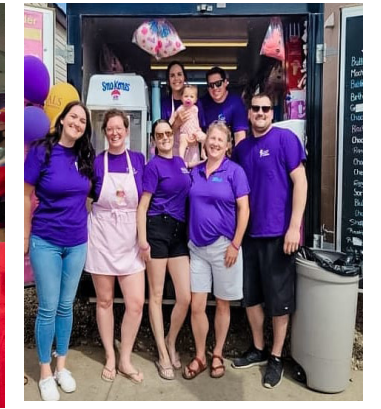
We know that 2022 will bring back some in-person events as restrictions continue to be eased. This will allow us to reconnect with clients and families across the province. The grey cloud in many ways has lifted, and we are thankful for our families, board, staff and supporters for their unwavering determination through the pandemic.



Gord Banting, CPA, CMA



THANK YOU!





The ALS Society of Alberta



7874 10th Street NE, Calgary, AB T2E 8W1 | Toll Free: 1-888-309-1111

Fax: 403-228-7752 | Email: info@alsab.ca | www.alsab.ca

5418 97 Street NW, Edmonton, AB T6E 5C1 | | Email: societynorth@alsab.ca | www.alsab.ca