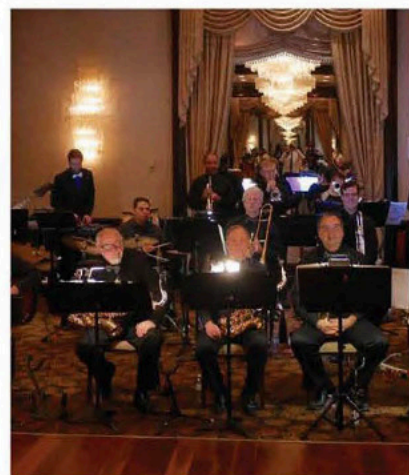
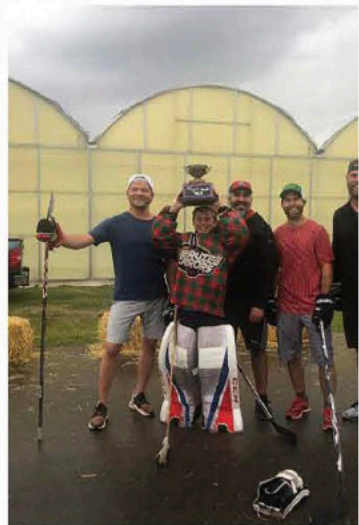
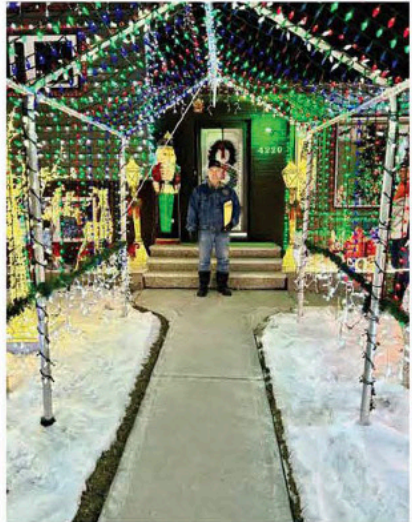


# 2022 Annual Report

## 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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# Board Chair Message

**Nancy Lyzaniwski**  
Chair, Board of Directors



A handwritten signature in black ink that reads "Nancy Lyzaniwski". The signature is fluid and cursive, matching the name in the caption above.



Our ALS community is drawn together by a terrible disease. We stay together because of our shared commitment to support those with the diagnosis and to help fund the continued quest to find treatments and a cure.

This past year, our community welcomed the long-awaited return of in-person events, enabling us to gather in incredible ways to help the Society fulfill its mission to make each day the best possible day for those living with and affected by ALS. The sense of togetherness that comes with seeing familiar faces and re-establishing personal connection has been rejuvenating. Personal connection is the epitome of our community's strength as we stand united in our fight against ALS at our annual Walks, Betty's Run for ALS, and other gatherings that often exceed their own fundraising targets. Thankfully, in-person events will continue to take place, creating more opportunities for us to unite and support each other. The fundraising at these events allows the Society to remain self-sufficient without seeking operational funding from government.

Thank you to the Society's Executive Director, Karen Caughey, who after leading the Society for 16 years, will retire mid-2023. Karen has been unfaltering in her exemplary leadership, compassion for our families, and dedication to raising funds and awareness of ALS. The Society has flourished under her stewardship and is positioned to continue positively affect countless families in the future. Thanks to her always careful and thorough planning, the transition to her successor will be seamless in the new year.

Thank you to our families, donors, partners, and volunteers for being constant sources of inspiration and motivation. Thank you to the staff and my board colleagues whose tireless dedication, passion, and perseverance help us live our mission.

## 2022 Board of Directors

**Nancy Lyzaniwski**  
Chair

**Tara Pentney**  
Past Chair

**Gord Banting**  
Treasurer

**Jim Robinson**  
Secretary

**Heather Haddow**  
Director

**Cathy Martin**  
Director

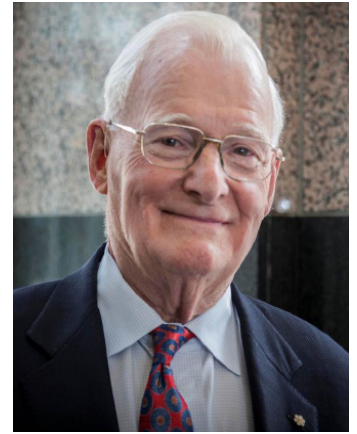
**Pamela Keenan**  
Director

**Kimberly Howard**  
Director

**Tom Gee**  
Director

**Karen Caughey**  
Executive Director

# Honourary Chair Message



I am honored to share with you the outstanding accomplishments and continued dedication of the ALS Society to families in Alberta throughout 2022.

As the Society and its staff continued to adapt as changes continued, the Client Services Team maintained its online support system and Equipment Loan Program. An impressive 78 support groups welcomed ALS clients, caregivers, and their family members in 2022. Keeping these support groups online meant that individuals from across Alberta could continue to meet with others and make connections.

The Equipment Loan Program maintained exceptional delivery and service standards, providing 1586 pieces of equipment to Albertans living with ALS across the province. With the rapidly growing needs of ALS families, our ability to maintain this essential program with such accuracy is impressive. I am proud of the work our staff and volunteers accomplish to make this happen.

Events in 2022 saw a shift back to in-person attendance – and our dedicated community was eager to reconnect with enthusiasm. Walk Together for ALS and Betty’s Run for ALS both saw significant growth, raising over \$ 974,000 between the two! This is possible thanks to the support of our partners, donors, participants, volunteers, and staff. These funds are essential in helping the ALS Society of Alberta fulfill its mission of making every day the best possible day for those living with and affected by ALS in Alberta as well as funding important ALS research. I am humbled by the growing support the Society receives each year.

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

# Programs and Services

The ALS Society of Alberta continued to ensure programs, services, and support were not disrupted in 2022 as restrictions were eased post-pandemic. As in years past, our essential service status allowed us to continue to provide assistance to families through our Equipment Loan Program and support groups. We continued our support services in a virtual model and maintained genuine connections – demonstrating our unwavering commitment to our families.

## Support Groups

Considering each of our family's unique situations, preferences, and desire to connect with one another in a safe way, our support groups remained online in 2022. The virtual format was well-received, it is accessible and allows clients to join in from anywhere. This provided our families with a routine that continued to foster our community's sense of strength and resiliency. In 2022, 78 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 2022. Each telephone call, text message, email, and video call made up 5983 points of contact and engagement with our 440 families living with ALS in Alberta.

## Equipment Loan Program

The Equipment Loan Program continued to provide outstanding service throughout 2022, ensuring the timely delivery of much-needed medical equipment to our families. Over the year, 1586 pieces of equipment were loaned to our families, as our team worked to ensure that clients were able to continue living safely and comfortably in their homes for as long as possible.

## Events

Over 90% of our events, such as Walks Together for ALS across the province, Betty's Run for ALS, and nearly all community events, returned to in-person. Our community showed great strength over the past few years and reuniting with one another brought us even closer. Everyone came together showing overwhelming community support. Thank you to our partners, sponsors, donors, and participants that made it all possible!

# 2022 Numbers at a Glance



**440**  
Families  
Supported

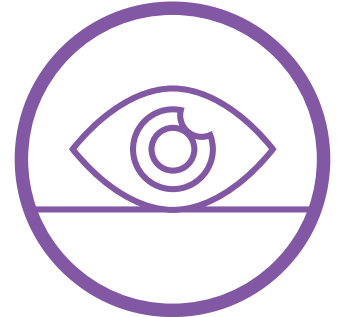


**1586**  
Pieces of  
Equipment  
on Loan

**78**  
Support Group  
Sessions



**5983**  
Client  
Check-ins



**12**  
Walks & Runs  
for ALS



**16**  
Community-led  
Fundraisers

**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 the organization. Each member dedicates their valuable time, resources, and expertise to lead and govern the Society, ensuring we continue to fulfill our mission, “to make each day the best possible day for people living with and affected by ALS”.

The Board of Directors’ 2022 annual planning session was dedicated to a discussion on furthering the funding and development of ALS research in Alberta. A strong commitment to build upon the Society’s existing dedication to ALS research was reaffirmed and continues to serve as a stepping-stone for future action.

Promising research continues at the University of Calgary and the University of Alberta, and the Board discussed the creation and funding of a fellowship model to build upon the province’s existing knowledge. The decision was then made to pursue supporting research in Alberta through funding two multi-year fellowship competitions. The Society knows that strong relationships with researchers and clinicians, and directing funds towards this fellowship model will build increased capacity for promising research developments. This represents an exciting new chapter in the world of ALS research, in Alberta specifically. This fellowship competition will raise awareness, and allow for increased partnerships and collaboration between leading Alberta-based ALS researchers and clinicians.

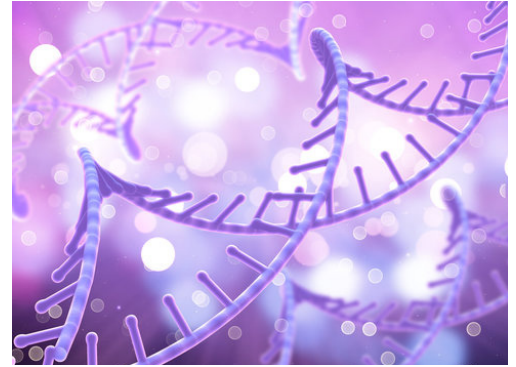
Additionally, we continue to partner with the provincial health coalition and other groups advocating for issues that affect Albertans living with ALS. Access to new treatments in a timely manner is a priority for people living with ALS. As new treatments become available, it is critical for our provincial and federal governments to approve these options promptly.

Albertans are responsible for more than \$8 million in donations to research via the Society, thanks in large part to Betty’s Run, Walks Together for ALS, and additional third-party fundraisers in Alberta. Albertans are some of the most active advocates in the country. It is through the collective voice of our community that change happens. Alberta’s ALS community, made up of families, volunteers, supporters, and staff members show admirable dedication in fulfilling our mission. Looking forward, we are thankful for the board’s support and guidance as we forge ahead, never losing sight of our goal or our focus on our families.



# Research and Education

The ALS Society of Alberta proudly continued its support of ALS research in 2022. This is a time of hope in the ALS research community, as researchers work to better understand the disease and find effective treatments.



Alberta is home to many world-renowned researchers who are committed to researching ALS and finding answers. Multiple clinical trials continued in both Edmonton and Calgary in 2022, in collaboration with pharmaceutical companies.

An ALS Patient Education event was hosted in summer 2022 by The University of Calgary Motor Neuron Disease Clinic, Calgary's ALS Clinic and the Alberta Neurologic Centre at the South Health Campus in Calgary. This event included presentations by ALS neurologists Dr. Sameer Chhibber, Dr. Theo Mobach and Dr. Gordon Jewett. Attendees were introduced to the new ALS therapeutic advancement Albrioza™, and Xeomin®, a form of Botox® to treat excessive drooling. After the educational session, enrollment was available for Albrioza™ and Xeomin® injections were accessible on-site. This early access to Albrioza is truly unique and we are thankful for the work of all involved.

Several studies and clinical trials were completed in 2022:

*Study of ANX005 in Adults with Amyotrophic Lateral Sclerosis (ALS) included a multi-center, open-label study of intravenous administration of ANX005 in patients with ALS.*

*A Study to Evaluate Safety, Tolerability, Pharmacodynamic (PD) Markers, and Pharmacokinetics (PK) of AP-101 in Participants with Amyotrophic Lateral Sclerosis (ALS).*

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, creating 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 are playing a major role in the global effort to understand and treat ALS.



# Public Awareness

Mikael and Frida Backlund continued their longtime support of our families throughout 2022. The Backlunds' ongoing dedication to our cause has been paramount in raising awareness about ALS. In 2022 they worked with Alberta Apparel, and created a black sweater with a custom-made front graphic that incorporates Mikael's number and signature celebratory move. On the sleeve, a small design is visible reading "making memories". Our ALS community is grateful for the memories Frida and Mikael facilitate each month by inviting families from our ALS community to Flames games.



Our social media presence and following continued to grow in 2022. Facebook remains our furthest reaching, gaining more than 141 new followers over the course of the year. Videos show to be one of the most effective means of raising awareness, with over half of our Facebook following sharing our videos on their own page. Our Instagram gained 44 new followers over the year. Our presence on social media and relationships with community members with strong influences have made a significant impact to both the growth in awareness about ALS and to our own reach.

# Making it Possible

"Making It Possible" is an awareness campaign featuring the personal narratives of families living with and affected by ALS in Alberta. These stories recount their experiences with the disease and show how the Society has enhanced their quality of life.

Every year in June (ALS Awareness Month), the Society encourages the ALS community to share their personal stories – including moments and treasured memories, with the support of loved ones and caregivers. In 2022, a total of 30 "Making it Possible" stories were submitted from all over Alberta and shared via social media and our official website.



# Grants and Foundations

The ALS Society of Alberta continued to diversify funding opportunities in 2022 and received grants from The Calgary Foundation and the City of Edmonton.

- **Investment Operating Grant** (CIOG) in 2022, once again the City of Edmonton stepped up to help the Society maintain and enhance client services in the Edmonton and surrounding area.
- **Strategic Opportunity Grant** , in 2022 the Calgary Foundation provided grant funding, contributing to the operational needs of the Society.

These grants help us continue to fulfill 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 organizations in 2022.



# Resource Development



## Betty's Run for ALS

The 26th Annual Betty's Run for ALS was a success, due in large part to the growing momentum from years past and the efforts of our community.

The success is a testament to the dedication, collaboration, and generosity of Alberta's ALS community. Despite the obvious challenges, teams and individuals came together to raise funds and spirits for those those living with and affected by ALS in Alberta.

In Betty's Run's 26-year history, over 9 million dollars has been raised for client support services and research - all while celebrating hope, care, and community. In 2022 alone, 80 teams, composed of nearly 800 participants impressively raised over half a million dollars (\$534,727)!

Our deepest gratitude is extended to the entire 2022 Betty's Run for ALS Planning Committee, our generous sponsors, volunteers, donors, participants, and supporters. 2022 was a notable milestone for Betty's Run and made many significant impacts on the Society's programs and services.



## Alberta Walks Together for ALS

In 2022, the majority of our Walks for ALS throughout Alberta returned to in-person. Participating communities in 2022 were: Altario, Camrose, Cold Lake, Drayton Valley, Edmonton, Hinton, Lethbridge, Wainwright, and Red Deer, while other communities participated virtually. Over 712 individuals making up 89 teams participated in the Walks province-wide, raising over \$414,000!

The ALS Society of Alberta extends their gratitude to each of the Walk coordinators and committee members, participants, sponsors, donors, and volunteers for their support and efforts throughout the year. The funds raised at the 2022 Walks contribute directly to the Society's ability to fulfill its mission and maintain its programs and services.

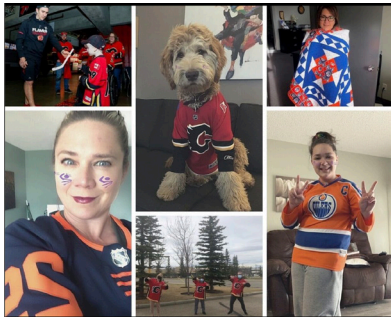


# Community Events

Community Events and Fundraisers were back in business in 2022!

We were thrilled to see the ALS Alberta Community spirit persevere and come back, stronger than ever. Over the course of the year, close to a quarter of a million dollars (\$224,802) was raised by third-party and community events alone.

Here are just a handful of the community events and fundraisers that happened in 2022.



- Adam's Pale Ale Fundraiser - Seachange Brewery
- Jim Davey Memorial
- Howard Smith Memorial ALS Roping
- Walk Together for ALS
- Betty's Run for ALS
- Drayton Valley Dueling Pianos
- ALS Run for the Cure
- Barrel Race Allan Simon
- Bridge Tournament & Lobster Feast
- Karen's Purple Shirt Part 3 on 3 Tournament
- Saz's Soldiers Golf Tournament
- Calgary Flames
- Blonde Ambition
- Devil's Head 'Moments' Coffee
- Strings For A Cause
- Quonset Days & Quonset Galas
- Cold Lake Swing for ALS
- Dutchess Florals
- Drayton Valley Duelling Pianos
- Larry's Holiday Light Up
- The Awesome Lemonade Stand
- Swing for ALS Golf Tournament
- Altario School Walk Together
- Family Dance Together for ALS

# Treasurer's Report

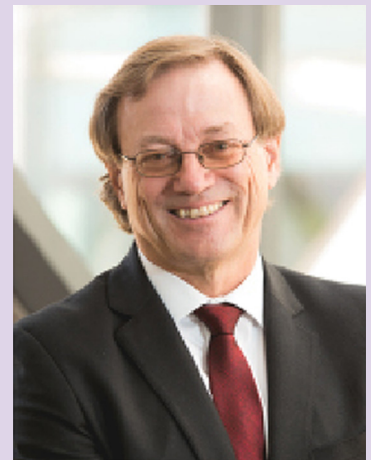
Looking back on 2022, it is heartwarming to see the resiliency of the ALS Society of Alberta's staff, volunteers, and families. While this past year had its fair share of ongoing challenges, it is evident that our community's dedication to fundraising remained a priority. This year, major fundraising events revenue grew again, making up an impressive 64 percent of total revenue in 2022, compared to 60 percent in 2021 and just 50 percent in 2020.

As in past years, our Client Service Team and Equipment Loan Program continued providing exceptional support to our families. In-person visits remained online, and our staff were proactive in finding adjustments to support clients' individual needs. Equipment and Client Services costs rose slightly as the percentage of total costs grew from 50 to 53 percent, confirming that the needs of our families continue to grow. The Society's support services continue to be a vital factor in our efforts to keep those living with ALS safely in their homes for as long as possible.

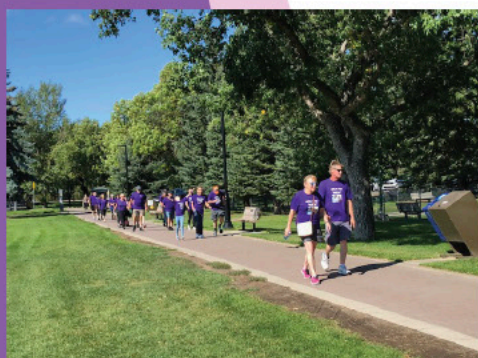
Revenues for 2022 totaled \$2.1 million, slightly more than 2021, while total expenses in turn totaled \$1.9 million less than 2021 at 2.1 million. The liquidity of the Society remains healthy, with a total of \$3.4 million in investments.

We know that 2023 will continue to see increased in-person events and attendance province-wide. This will allow us to reconnect with clients and families across Alberta. We are incredibly grateful to our families, board, staff, and supporters for their unwavering dedication to our cause.

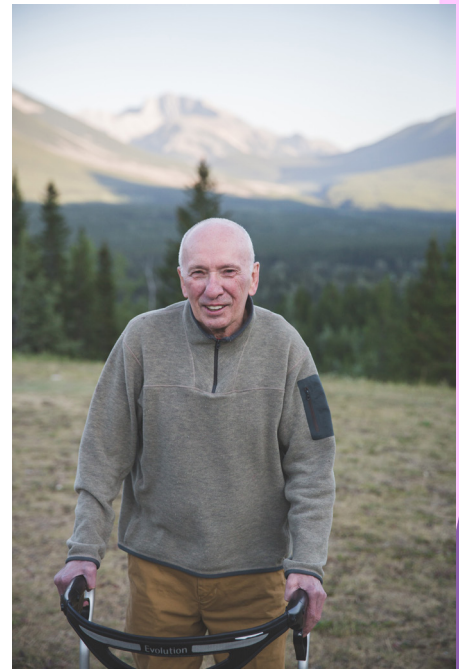
**Gord Banting, CPA, CMA**



# THANK YOU!









# The ALS Society of Alberta



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