

# Prairie to Peak

A PUBLICATION OF THE ALS SOCIETY OF ALBERTA  
OCTOBER 2020



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# Message from our Executive Director, Karen Caughey



Fall greetings to all in our ALS Alberta community!

I don't normally include a personal note in our newsletter, but I wanted to reach out to all of our supporters and families this fall, as I know so many of us are going through difficult times with the COVID-19 pandemic.

In addition, due to the many changes that we have faced as a Society during this crisis, we have not had a newsletter in quite some time. I wanted to provide an update to recap the past year while also looking towards the future.

While COVID-19 has had negative impacts on so many areas, we have been adapting and pivoting wherever possible to continue to serve our resilient community here in Alberta. Our support groups have moved online, which has allowed people from all over the province to connect in a way they couldn't before the pandemic. Support groups are no longer limited to urban centres, and many of our rural clients are now taking part, often doubling the size of the group. In addition, our Client Service team has maintained communication with our clients online and via phone. While we can't wait to return to in-person visits, we are glad to still be able to connect with you all in whatever ways we can. We have also worked hard to get equipment to our clients as consistently as possible, even during the height of the pandemic. We all know that ALS doesn't stop or pause because of COVID-19.

As with other charities and businesses, we have also had to deal with the harsh financial realities of the COVID-19 pandemic. We have had a dramatic reduction in revenue this year, due to the impact of the restrictions forcing the cancellation and/or modification of most of our fundraising events. In a normal year, our fantastic community would host 40 to 50 fundraisers, while we of course would work with our wonderful volunteers to organize Betty's Run for ALS in Calgary and Walks to End ALS across the province. Those two key events both switched to an online format in 2020, and while the dollars raised might not have equaled past years, our virtual events on June 21st were a great moment of pride for us all. We watched our community unite online and from a social distance, and were inspired by everyone's commitment and passion.

As a charity that receives no government funding, we rely on fundraising and donations to maintain our programs and services. As such, we are currently working hard on alternate sources of funding, such as grants, online fundraisers and other avenues, some of which you will read about on the pages to follow. Giving Tuesday on December 1 will be a significant campaign at the end of this year, and we will be sharing more information in the coming weeks. If you have fundraising ideas of your own that you would like to discuss with us, please don't hesitate to reach out. 2020 is a year unlike any other in our history, and we are looking for ingenuity in 2021 to ensure we can continue to make each day the best possible day for those living with and affected by ALS.

Best regards,

A handwritten signature in black ink that reads "Karen Caughey". The signature is written in a cursive, flowing style.

Karen Caughey

# Upcoming Fundraisers

## Giving Tuesday - December 1, 2020

Join us for the 8th annual Giving Tuesday on December 1, 2020!

Giving Tuesday is a global movement for giving and volunteering, taking place each year after Black Friday and Cyber Monday. The “Opening day of the giving season,” it’s a time when charities, companies and individuals join together and rally for favourite causes. Last year, the ALS Society was fortunate to raise almost \$6000, and we are looking to beat that total this year at a time when donations are more important than ever. It will also be our kick off to a year-end fundraising campaign for the ALS Society of Alberta. Please help us raise funds to keep the important work of the ALS Society of Alberta going in 2021. More information to follow via social media and email in the coming weeks.

### Highlander Wine & Spirits Fundraiser

Wine lovers, we are giving you plenty of advance notice!

On May 12, 2021, the ALS Society of Alberta will be Highlander Wine & Spirits’ Give Back Partner! From noon on May 11 to noon on May 12, 50 per cent of the profits of the sales will be donated to the ALS Society of Alberta. Previous Give Back partners have raised up to \$10,000, so we hope you will plan your summer wine purchases to coincide with May 12!



## Facebook Fundraisers

Under the current restrictions of COVID-19, we know that many of you have had to cancel or adjust your scheduled events this year and have inquired about possible alternatives. Facebook’s fundraising option is one such option. Facebook can be a quick and easy way to raise money and engage your network of friends and family, especially during this time of physical distancing.

Anyone can create a fundraiser for the ALS Society of Alberta - donations are processed at no cost to the society or the individual, and receipts are sent straight to donors. We have had some of our community hold birthday fundraisers and general donation requests in place of in-person events.

Go to [facebook.com/fundraisers](https://facebook.com/fundraisers) to get started and for more details, or contact Meaghan or Paula at [alscommunications@alsab.ca](mailto:alscommunications@alsab.ca) if you would like some additional information or any assistance.

***We are open to any fundraising ideas that you might have! Corporate partnerships, matching programs, food and beverage campaigns... get in touch and let us know what you think!***

# Making it Possible - Mikael and Frida Backlund

While the 2019-20 NHL regular season unfortunately came to an abrupt end, we were so blessed once again that Mikael and Frida Backlund continued to host our families at Calgary Flames games up until the season's early completion. As in past years, the chance for our families to watch a game and also meet Mikael was a complete thrill. Every season, Mikael also generously donates \$200 per point to the ALS Society of Alberta. To ensure we were still supported during the events of this pandemic, Mikael and his wife Frida donated \$10,000, matched in full by the Flames Foundation and KPMG.

Mikael and Frida, we can't thank you enough for your ongoing support, and the difference you make in our families' lives. Attending Flames games as your guests provides lasting memories that stay with our families forever. Thank you so much!



*"Love this guy... loved the smile he  
put on Jessie's face.  
Thank you Mikael!"*



# Making it Possible - An Evening of Appreciation

Last November, the ALS Society of Alberta hosted an Evening of Appreciation. Events were held in both Calgary and Edmonton, and it was an evening for our families, volunteers, donors, staff and community partners to come together.



**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**



**Walk to End ALS Award**  
**Cheryl Feth - Camrose**



**Norman Pollock - Exceptional Volunteer Award**  
**Jim McLaughlin**



**Exceptional Fundraising Program**  
**Howard Smith Memorial Team Roping**



**Exceptional Fundraising Program**  
**Sylvia Tensfeldt**



**Long-term Service**  
**Tara Pentney - 15 years**



**Long-term Service**  
**Christy Reschke - 5 years**



**Exceptional Fundraising Program**  
**Gish Warriors**



**Long-term Service**  
**Nancy Lyzaniwski - 5 years**

# Community Support



## Puck Drop Fundraiser

Ewan Sinclair & Daughter Melanie Florax took part in the Puck Drop Fundraiser in Spruce Grove, AB. Melanie raised \$1500 to thank the Society for all of the help they've provided her father. Thank you!



## Bleeds Green Final Tribute Show

Thank you to Bleeds Green for partnering with the Society to raise funds and awareness through a 50/50 at their show last November. A special thank you to Curtis Campbell, the winner of the draw, who donated his winnings back to the Society.



## Judy Schweitzer ALS Curl for a Cure

The 10th annual Judy Schweitzer ALS Curl for a Cure took place last November in Red Deer, and once again was a huge success. There were 48 curlers who took to the ice, raising funds and awareness for ALS. Thank you to Carrie Mello, and all of the friends and family that make this event happen each year.



## General Presidents' Maintenance Committee for Canada

This year, the GPMC and its affiliated trade unions chose the ALS Society of Alberta as one of their charity initiatives. Pictured: Danny Getzlaf, Nancy Lyzaniwski, Sheldon McKenna



## Medicine Hat High School Bball Slam Dunk ALS Games

On Feb. 28th, 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 going to the ALS Society. Over \$3000 was raised!



## MCG Simmentals and Rack Red Angus Bull Sale

In March, we were fortunate to attend the MCG Simmentals and Rack Red Angus Bull Sale in Stavely, AB, at the invitation of the Brown family. 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.

# Community Support



## F12 Partnership

Thank you to F12, our IT company, for making your annual donation to the Society! Your support means so much to us!



## Jesse's First Birthday Fundraiser

Our little friend Jesse had his first birthday party and he and his family wanted to do something special to remember their good friend Jim Park. Jesse's mom asked all of his friends and family to donate to the ALS Society of Alberta in lieu of gifts. We are in absolute AWE that Jesse and his family were able to raise over \$500 for the Society!



## Bob Rock Memorial Golf Tournament

It's official – the 4th Annual Bob Rock Memorial Golf Tournament and ALS Fundraiser is in the books. 90 golfers enjoyed a glorious day in sunny Arizona at The Links at Queen Creek and over 200 guests shared an amazing dinner and opened their hearts and wallets for the ALS Society in memory of a great man...raising \$7000 for the ALS Society of Alberta and Arizona.

Bob Rock, cowboy and golfer - husband, dad, Pops, son, brother and friend lost his two year battle with ALS in October 2016, and family and friends have gathered to celebrate him for the past four years by joining in a sport he loved and to help our family give back to the ALS Society. And yes, plans are already underway for the 5th Annual Bob Rock Memorial – January 31, 2021 is the target date.



## "It's In The Bag" Event

20% of sales (\$5322) came to the Society from Village Fashions in Spruce Grove, AB. Thank you so much for your support through this event!



## Altario Students' Winter Events

Altario Students raised \$10,000 in honour of their teacher currently living with ALS, Mrs. Kari Evans. 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!

# Betty's Run for ALS & Walks to End ALS ... *virtual editions!*

In March of 2020, the Betty's Run Planning Committee and Walk to End ALS Coordinators across the province were busy planning their upcoming events. In fact, we were just about to head to Edmonton for a training session when COVID-19 hit and changed how events around the world would take place in 2020. As a team we pivoted, learned from others, and developed a virtual event like no other.

The Betty's Run and Walk to End ALS communities proved our ability to adapt and come together as a provincial force. We walked, rode, rolled and ran alone and in groups, as families or socially distanced, to raise money for those living with ALS in this province, as well as towards the Canadian ALS Research Program.

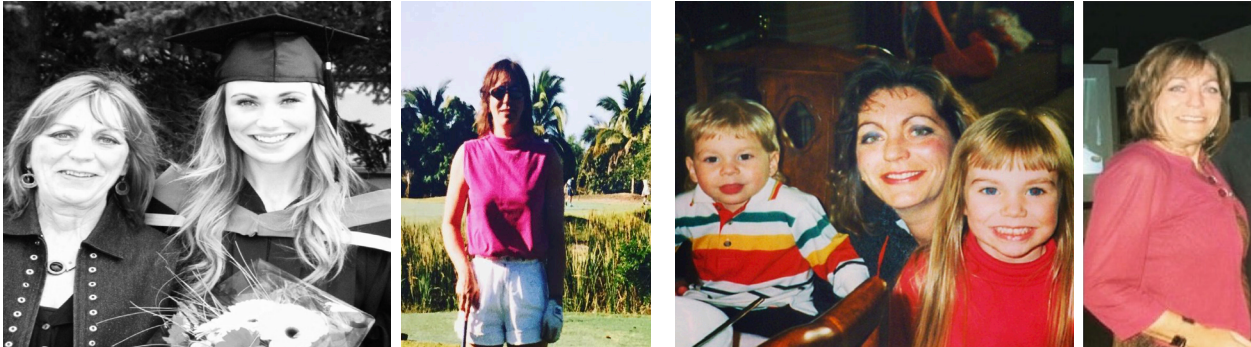
We hope to be back together in-person next year, but are proud of the virtual event that occurred on June 21, 2020. Seeing your faces on Facebook and Instagram all day and compiling all of the videos and slideshows was a remarkable experience. Not to mention we managed to raise in total over **\$540,000**, despite all of the challenges created by COVID-19. Thank you to all of our dedicated families and friends!

If you are interested in starting a walk in your community in 2021, please let us know!





# Featured Fundraiser - Laura Plantje



When Laura Plantje talks about her mom Janice, the love and admiration that shine through her words are incredibly heartfelt. You wish you had known this fun-loving woman whose family was the light of her life, and who raised her children with integrity, strength and unconditional love. An avid golfer and skier that could turn a dinner party into a dance party, Janice saw the potential in people and was a bright light in the lives of everyone she knew. Speaking with Laura, you can sense that this amazing woman is now missed every single day by those that loved her.

Janice passed away on January 22, 2014 from ALS, and like most of us who have lost someone to the disease, the years of living with ALS as a family were a lot to look back on and deal with in the years immediately following. This year though, in 2020, Laura felt ready to get involved with raising awareness of, and funds for, ALS. It felt like the right time to tell her mom's story and make an impact in the fight against ALS in Janice's name - and working for Benevity, she had the perfect work environment to make the most of this idea.

Benevity is a Corporate Matching/Community investment/Employee Engagement software company, that helps companies around the world make an impact while supporting employees and giving back to the community. Many corporations use this as their corporate matching program software – and as an employee of the company, Laura was provided with some fantastic opportunities to create a giving opportunity to the ALS Society of Alberta.

Laura set up a giving page that was accessible both internally to colleagues and to friends and family via an external link. Nervous about reaching out to colleagues, she launched her campaign on the morning of January the 22nd, the sixth anniversary of her mom's death, with a goal of \$1000. By the time Laura arrived at work that morning, she had already exceeded that goal, and by the end of the day, the total was \$10,000. The final fundraising tally for Laura's campaign was nearly an astonishing \$14,000! The generosity of her friends, family and colleagues, as well as the subsequent corporate donation from Benevity, has been nothing short of amazing, and again shows how much Janice was loved, and is now missed.

This incredibly generous donation to the ALS Society of Alberta, comprised of so many individual donations in honour of Janice, means so much to us. Every dollar raised this year is incredibly important, to help ensure that we can continue to support Albertans with ALS despite the substantial decrease to our fundraising revenue and lack of government support.

If you have done a personal fundraising campaign, please reach out and let us know so that we can share your story, either in our newsletter or on social media. Or, if you need some help getting started, our team will be happy to help! Thank you, Laura, for sharing your mom's story and for your incredible work this year in raising funds and awareness in her name.

## DOES YOUR COMPANY USE BENEVITY?

### ONLINE GIVING AT WORK

Laura was able to maximize her giving campaign by using Benevity's Spark software, so her colleagues, friends and family could all donate to a cause close to her heart - with matching dollars provided by her employer.



Check with your HR team to see if you currently use Benevity, or another program, to promote fundraising campaigns and/or match your donations!

# Research Update

The ALS Society of Alberta is proud to be one of the largest contributors to the Canadian ALS Research Program directed to finding the cause of, and a cure for ALS. Albertans have been very generous in dedicating time and funds to support ground breaking research - in 2019, Albertans contributed more than \$360,000 to ALS Canada's research program through Betty's Run for ALS, Walks to End ALS, Orange Theory fundraisers and other individual contributions.

## Clinical Trials

Clinical trials are research studies that use human volunteers to test new therapies. After scientists test experimental therapies in the laboratory, those with promising results move to clinical trial to determine whether the therapy is safe and effective for use in humans. You can learn more about the clinical trials currently being conducted in Alberta, listed below, on our website at [www.alsab.ca](http://www.alsab.ca), or visit [ClinicalTrials.gov](http://ClinicalTrials.gov), where all legitimate, recognized ALS clinical trials are registered globally.

### **Safety Study of Oral Edaravone Administered in Subjects With ALS (MT-1186-A01)**

Study Type: Therapeutic (Edaravone); Phase 3

Status: Active, not recruiting

Sites: Edmonton, Calgary, Montreal (Neuro), Greenfield Park

Sponsor: Mitsubishi Tanabe Pharma Development America, Inc.

### **A Clinical Trial of Pimozide in Patients With Amyotrophic Lateral Sclerosis (ALS) (Pimozide2)**

University of Calgary

Study Type: Therapeutic Study (Drug: pimozide); Phase 2

Status: Recruiting

Sites: Calgary, Edmonton, Toronto, Montreal (CHUM), Montreal (Greenfield Park), Fredericton, Hamilton, London, Ottawa.

### **Phenotype, Genotype & Biomarkers in ALS and Related Disorders**

University of Miami (Site is in Edmonton)

Study Type: Observational Study

Status: Recruiting

### **A Study to Evaluate the Efficacy, Safety, Tolerability, Pharmacokinetics, and Pharmacodynamics of BIIB067 Administered to Adult Subjects with Amyotrophic Lateral Sclerosis and Confirmed Superoxide Dismutase 1 Mutation**

Study Type: Therapeutic (BIIB067); Phase 3

Status: Recruiting

Sites: Toronto, Montreal (Neuro), Calgary

Sponsor: Biogen

Collaborator: Ionis Pharmaceuticals, Inc.

### **A Phase 1 Multiple-Ascending-Dose Study to Assess the Safety, Tolerability, and Pharmacokinetics of BIIB078 Administered Intrathecally to Adults with C9ORF72-Associated Amyotrophic Lateral Sclerosis**

Study Type: Therapeutic (BIIB078); Phase 1

Status: Active, not recruiting

*\*possible new upcoming cohort opening*

Sites: Calgary, Edmonton, London, Toronto, Montreal (Neuro & CHUM)

Sponsor: Biogen

### **Novel MRI Biomarkers for Monitoring Disease Progression in ALS**

Study Type: Observational

Status: Recruiting

Sites: Edmonton, Calgary, Toronto, Montreal (Neuro), Quebec City

Sponsor: University of Alberta

# Research Update

## University of Alberta Update

### Enrolling Clinical Drug Trial:

**Pimozide: a Phase 2, randomized, placebo-controlled, double-blind, multi-centre study that will evaluate the safety and effectiveness and how well it is tolerated in people with ALS.**

Study duration is 26 weeks. There are 9 in-person (at clinic) visits.

To read more about this trial, you can go to:

<https://clinicaltrials.gov/ct2/show/NCT03272503?recrs=ab&cond=ALS&cntry=CA&draw=2&rank=2>

### Coming Soon Trials: (pending Ethics and Institute Approval)

**Edaravone (RADICUT®) : A Phase 3b, Multicenter, Randomized, Double-Blind Study to Evaluate Efficacy and Safety of Oral Edaravone Administered for a Period of 48 Weeks in Subjects with Amyotrophic Lateral Sclerosis (ALS)**

Study duration is approximately 58 weeks. There are 8 in-person (at clinic) and 8 phone visits.

To read more about this trial, you can go to:

<https://clinicaltrials.gov/> ClinicalTrials.gov Identifier: NCT04569084

**Ravulizumab: a Phase 3, Double-Blind, Randomized, Placebo-Controlled, Parallel Group, Multicenter Study With an Open-Label Extension to Evaluate the Efficacy and Safety of Ravulizumab in Patients With ALS.**

Study Duration is approximately 160 weeks. There are 26 in-person (at clinic) visits.

To read more about this trial, you can go to:

[https://clinicaltrials.gov](https://clinicaltrials.gov/) ClinicalTrials.gov Identifier: NCT04248465

Staff Contacts: Kelsey Tymkow [tymkow@ualberta.ca](mailto:tymkow@ualberta.ca) 780-492-7690  
Shelley Wrona [wrona@ualberta.ca](mailto:wrona@ualberta.ca) 780-248-1329

### Research Communication Updates:

#### The ALS Talk Project

A big thank-you to everyone who participated in the ALS Talk Project focus group study. We have just wrapped up the final groups for people living with ALS and for family members/caregivers. We are looking forward to exploring the input we've had from people across the country and sharing the information with health care providers. Stay tuned! (Contact [als.talk@ualberta.ca](mailto:als.talk@ualberta.ca) for more information)

#### Quality of Life Scales

We are proud to support Canadian ALS research! We helped Drs. Dal-Bello Haas and Kuspinar and their team at McMaster complete the first phase in their project to develop a quality of life scale specifically for people with ALS. This research would not have happened without the participation of people with ALS from Alberta - thank you! Phase 2 is underway, so there are more opportunities to participate if you're interested. (Contact [vandaj2@mcmaster.ca](mailto:vandaj2@mcmaster.ca) for details)

# Research Update

## University of Calgary Update

### Possible Upcoming studies: (late 2020 or early 2021 start)

#### **A Phase 3, Multi-center, double-blind, randomized, placebo-controlled trial to evaluate the efficacy and safety of reldesemtiv in patient with ALS**

Sponsor: Cytokinetics

Trial Name: COURAGE-ALS

#### **A Phase 2b/3, Multi-centre, randomized, double-blind, placebo-controlled, 12 month clinical trial to evaluate the efficacy and safety of MN-166 (Ibudilast) followed by an open-label extension in subjects with ALS**

Sponsor: Medicinova

Trial Name: COMBAT ALS

#### **A Phase 3, Double-Blind, Randomized, Placebo-Controlled, Parallel Group, Multicenter Study with an Open-Label Extension to Evaluate the Efficacy and Safety of Ravulizumab in Patients with Amyotrophic Lateral Sclerosis (ALS)**

Sponsor: Alexion

Trial Name: CHAMPION ALS



## ALS Society of Alberta Board of Directors

The ALS Society of Alberta is governed by a Board of Directors. The Board is responsible for making each day the best possible day for families affected by ALS, and for the work of the Society and its standing in the community. The board members volunteer countless hours each year - thank you so much to our dedicated members of the board!

Due to the COVID-19 pandemic, this year's Annual General Meeting was held virtually, and the 2020-21 board was elected.

**Chair:** Nancy Lyzaniwski

**Past Chair:** Tara Pentney

**Treasurer:** Gord Banting

**Secretary:** Jim Robinson

**Director:** Heather Haddow

**Director:** Cathy Martin

**Director:** Kimberly Howard

**Executive Director:** Karen Caughey

## SUPPORT GROUPS

The ALS Society of Alberta offers support groups and information sessions to help people living with ALS, their families and caregivers. All support groups and information sessions are provided free of charge, and are offered in casual group settings that provide everyone an opportunity to share their experiences, information and support.

Due to the current situation regarding the COVID-19 virus, and in the best interest of our clients, the Society has moved all in-person support group meetings to an online format until further notice. This also allows clients from across the province to participate, no matter their urban or rural location.

If you would like more information about the groups, please contact Leslie at 403-620-1328/leslie@alsab.ca (South), or Christy at 780-487-0754/christy@alsab.ca (North).

### ALS SUPPORT GROUP

These groups provide support to people living with ALS, their spouses, significant others, friends and families. It gives individuals the opportunity to meet others on the ALS journey, share challenges and solutions, have some fun and socialize.

### ALS FAMILY AND SPOUSAL SUPPORT GROUP

These groups are for people who have or are currently supporting someone affected by ALS.

### STAYING IN TOUCH

This group was created for those who have lost someone to ALS

### PLS & KENNEDY'S

This group was created for those living with and affected by PLS, Kennedy's and other neuromuscular disorders.

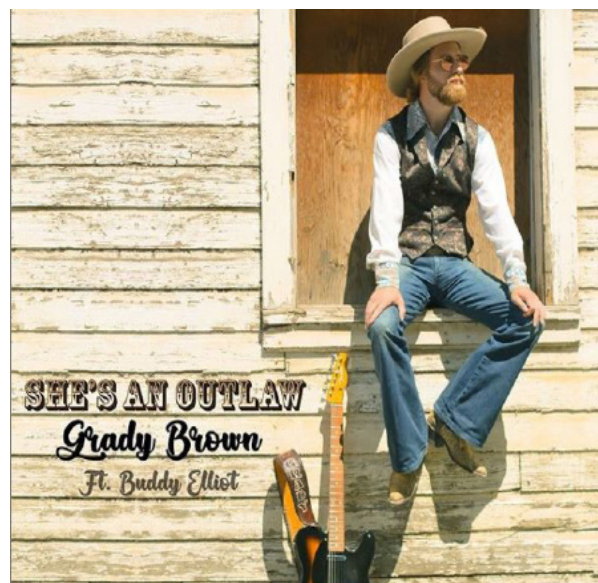
### Grady Brown Fundraiser

Alberta musician Grady Brown released his second radio single, "She's an Outlaw" on August 15. 100 per cent of the proceeds from this song go directly to the ALS Society of Alberta, in memory of Grady's grandma, whom he lost in August of 2019.

You can support both Grady and the ALS Society of Alberta by downloading/streaming the song on Spotify, Amazon Music, Google Play, iTunes, Apple Music, or wherever you find your music digitally.

Thank you, Grady for your support!

[facebook.com/GWBmusicAB](https://facebook.com/GWBmusicAB)



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



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## PLEASE CONSIDER MAKING A GIFT

Monthly donations are a key aspect of our fundraising efforts, as they provide a steady and predictable source of funding, allowing us to plan for the future. If you are interested in setting up a monthly donation plan, please contact the Provincial Head Office at 403-228-3857.

For one-time donations, please visit us online at [www.alsab.ca/donate](http://www.alsab.ca/donate), or fill in and mail the form below.

Thank you so much for helping make each day the best possible day for people living with and affected by ALS.

I am enclosing a one-time donation of (circle) \$25 \$50 \$100 \$250 other \$\_\_\_\_\_

Enclosed is a cheque payable to the ALS Society of Alberta

Please charge the above amount to my credit card (*Please call (403)228-3857 to set up credit card donations*).

Please send my charitable tax receipt to:

Last Name \_\_\_\_\_ First Name \_\_\_\_\_

Address \_\_\_\_\_

City/Town \_\_\_\_\_ Province \_\_\_\_\_ Postal Code \_\_\_\_\_

Phone \_\_\_\_\_ E-Mail \_\_\_\_\_

Please return this form to the ALS Society of Alberta's Provincial Office. Your gift will help us to make each day the best possible for those living with and affected by ALS.

*PRIVACY STATEMENT: Your personal information will not be traded, sold, or shared without knowledge or consent. For more information, please call the ALS Society of Alberta's Provincial Office.*

The Society aims to raise \$1,846,988 in donations with fundraising costs of approximately 12% in expenses.

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## CONTACT US

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