Prairie to Peak

A PUBLICATION OF THE ALS SOCIETY OF ALBERTA JULY 2019





Making It Possible

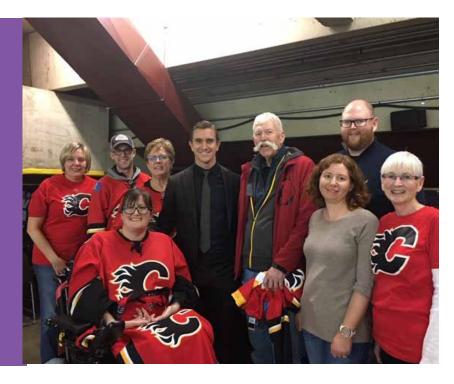






Mikael and Frida Backlund generously donate tickets to our families each month, and host us at a Calgary Flames Game.

Since 2015, Mikael and Frida have hosted more than 64 families at these games. This experience creates lasting memories for our families and we are so grateful for Mikael and Frida's support!



Meet the 2019 Ambassadors

Each year, the Betty's Run for ALS Committee and Walk to End ALS Committee selects an Ambassador to represent the Society and be the spokesperson for Betty's Run and the Walk to End ALS.

The ALS Society of Alberta is thrilled to share the stories of Ken McIsaac the 2019 Betty's Run for ALS Ambassador, Danny Getzlaf the 2019 Edmonton Walk to End ALS Ambassador and Ken Rusk the 2019 Hinton Walk to End ALS Ambassador



Ken McIsaac, 2019 Betty's Run for ALS Ambassador

You can read Ken's story at https://www.alsab.ca/bettysrun



Ken Rusk, 2019 Hinton Walk to End ALS Ambassador

You can read Ken's story at:
https://www.alsab.ca/
news/2019/4/25/2019-hinton-walk-to-endals-ambassador-ken-rusk



Danny Getzlaf, 2019 Edmonton Walk to End ALS Ambassador

You can read Danny's story at: https://www.alsab.ca/news/2019/3/15/ introducing-the-2019-edmonton-walk-toend-als-ambassador-danny-getzlaf

Honouring Dave Williams



In January, we said goodbye to Dave Williams, a long time board member and good friend of the ALS Society of Alberta.

Dave was an active member of our board of directors since 2007. Dave led with wisdom, expertise and compassion. During the most significant growth of our organization, Dave's leadership was instrumental to the Society.

One of his many achievements was the awareness he brought to the Alberta Government about the ALS cause. He brought 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.

Thank You Mechanical Contractors Association of Canada (MCAC)



The ALS Society of Alberta is so honoured to be chosen as the charity of choice by MCAC for this year. Thank you!

At the 2019 MCAC Mid-year meetings, MCAC President Jack Bavis and the MCAC Board of Directors announced the ALS Society of Alberta as the charity of choice for this year in honour of past MCAC President David Flamand's sister Patsy Brooks.

To read a message from Patsy's Family please visit https://mcac.ca/about/charity/.

Thank You!

A heartfelt thank you to all the volunteers for our Edmonton Casino on Feb. 10 & 11, 2019 and our Calgary Casino on July 2 & 3, 2019. These casino events raise significant funds for the Society and we couldn't do it without the support of our volunteers!



Ariella's Birthday Donation

Ariella donated an impressive \$630 that she collected at her 6th birthday party. Ariella asked for donations toward the Society instead of gifts. Thank you so much Ariella!



Drayton Valley Bowling for ALS

The Drayton Valley Walk to End ALS Committee organized a bowling night on March 16 at Thunder Alley. 118 people attended the event that raised \$1,215 towards their Walk!



ALS Zumbathon

An impressive \$2,051 was raised at this fantastic event that saw over 100 people attend a Zumba class taught by ZJ Rony Gratereaut. Thank you so much for your support!



3rd Annual Bob Rock Memorial Golf Tournament This golf tournament held in Mesa, Arizona on January 26 raised an incredible \$6,500 this year. Thank you Lori Rock

for hosting such a fantastic event.



Alley Kat Brewery Launch Party Cask Night

Alley Kat Brewery raised an amazing \$2,485 in tips from their first quarter for the ALS Society. Thank you to everyone at the Alley Kat Family for your generosity!



Village Fashions "It's in the Bag" Event

Village Fashions will be hosting an event that with a minimum donation of \$20, you'll receive a reuseable bag which entitles you to fill your bag on the following Saturdays with 20% savings: August 31 and November 30.



Lessard Community League Spring Bazaar
On April 13, the Lessard Community League hosted their
Spring Bazaar with a raffle prize and a 50/50 draw, with the
proceeds going to the ALS Society. Thank you to everyone
who attended and donated!





Drayton Valley Walk to End ALS: Dueling Pianos
The Drayton Valley Walk Coordinators planned a very
successful Dueling Pianos event with Court Jester Dueling
Pianos. The event which included a silent auction,
raffle and generous donations raised a net amount of
over \$7,300! Thank you ladies for planning such a wellexecuted event!



Red Deer Walk to End ALS: Petal and Blum Terrarium Workshop
The Ped Deer Walk Coordinators held a Petal and Blum

The Red Deer Walk Coordinators held a Petal and Blum Terrarium Workshop on May 29 to raise funds toward their Walk.



Gish Warriors

The students at Elmer S. Gish School in St. Albert have been raising money since December 2018 until the end of June with events, lemonade stands and bottle drives. They have already raised an amazing \$10,000!

Aiden's Birthday Donation Helping other children was top of mind for Aiden when he donated his birthday money to Support For Champions. Thank you so much Aiden!





Claire and Adam's Awesome Lemonade Stand Katherine and Kris Andreychuk and their kids, Claire and Adam, held their annual Awesome Lemonade Stand for ALS on May 31. They raised an incredible \$3,633 toward their Walk Team (Team A-Bomb) for Adam Rombough, the 2018 Edmonton Walk Ambassador! Thank you so much for your continued support!



Danny Getzlaf Community Spirit Fundraiser
It was so incredible to see the spirit of the community come together for Edmonton's Walk Ambassador,
Danny Getzlaf's fundraising event. The event was held at Coach's Corner on June 1 and with a combined effort, an astounding \$11,950 was raised towards Danny's Team for the Edmonton Walk to End ALS! Thank you to everyone who stopped by to donate and participate.



Saz's Soldiers

The 8th Annual Saz's Soldiers Golf Tournament was held on June 1 in Beaumont at the Coloniale Golf Course. Fifty per cent of the funds raised were donated to the ALS Society! It was an exciting day with two holes in one during the tournament! Thank you Tanya Sasyniuk, for organizing another fantastic tournament!



Abagail and Tyler's Lemonade Stand

It may have been a chilly day but the determination of Abagail and Tyler was shining through. Abagail and Tyler set up a lemonade stand at the family garage sale in May and dedicated all of the funds they raised to the ALS Society of Alberta. Thank you Abagail and Tyler!



Kick-Off to Summer - Tiki Party

Tops Pizza and Steakhouse (South), with The Calgary Parrot Head Club held a Kick-Off to Summer Tiki Party on June 8th which raised \$2,100 for the Society. The event included a silent auction, raffle and 50/50 as well as fantastic music by pH Unbalanced. Many thanks to Tops Pizza staff and the Parrot Head Club for planning such a great event.







Karen's Purple Shirt Party

The second annual Karen's Purple Shirt Party was held on June 8th in Redcliff, Alberta. The event featured a 3-on-3 ball hockey tournament, a silent and live auction, great food and a performance by John Wort Hannam. Karen's Purple Shirt Party started last year to honour Karen Wagenaar. Her family worked tirelessly to hold the event again this year and we thank them for all of their hard work and dedication. Karen's Purple Shirt Party raised over \$23,000 for the ALS Society of Alberta this year – a tremendous success. These funds will make a significant impact on the lives of people living with ALS in Alberta.



Brooklyn Stands for ALS Nothing beats a cold glass of lemonade on a hot day. On June 8th, Brooklyn set up her lemonade stand in Okotoks and raised \$218 for the ALS Society of Alberta. Brooklyn was raising funds in honour of her dad who is living with ALS. Thank you Brooklyn for your support.



Kids with a Cause
On the 6th of June there was an
Awareness Fair at Masters Academy.
We are honoured that Mercedes chose
to do her project on ALS and featured
the ALS Society of Alberta. Mercedes
had the opportunity to visit our facility
and learn more about what we do and
she then shared it with her school.
Thank you Mercedes for helping build
awareness about ALS.



Stitchin' for Support
Sylvia Tensfeldt has been living with
ALS but hasn't let that diagnosis
prevent her from doing her favorite
things – including cross-stitching.
This year, Sylvia will be designing
an embroidery project that she
hopes to complete by the fall of this
year. The entire picture contains
approximately 40,000 stitches and
her goal is to raise at least \$1 per
stitch. To date, she has already raised
\$1,230! To donate online please visit:
https://bit.ly/2K7cEfc

2019 Walk to End ALS Kick-off Brunch

This year's Edmonton Walk to End ALS Kick-off Brunch was held on March 9, 2019 - what a fantastic day! Speakers included Board Member Nancy Lyzaniwski, Patti Courchesne, Terri Kezema, Mayor of Morinville, Barry Turner and 2019 Walk Ambassador, Danny Getzalf. Thank you to all who attended the brunch and to James H. Brown and Associates for their consistent dedication as a sponsor of the Kick-off Brunch and the Edmonton Walk to End ALS.

Betty's Run for ALS

This year was the 23rd Annual Betty's Run for ALS. The run took place on Sunday, June 9 in North Glenmore Park. Over the past 23 years, Betty's Run for ALS has raised over \$7.5 million for client support services and research. This event aims to celebrate, promote and channel hope to those affected with ALS, along with their families and friends.

Each year, the Betty's Run for ALS Planning Committee chooses an Ambassador to represent the Society and 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 and we thank him for being the 2019 Ambassador.

This year's event raised over \$380,000! 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.





Walk to End ALS

Edmonton

It was a beautiful day for the 2019 Edmonton Walk to End ALS on Saturday, June 8. Over 1,000 people gathered in William Hawrelak Park to celebrate the lives of people affected by ALS in Alberta, and to raise funds for client support and research. Thank you to all the volunteers, donors, supporters, participants and sponsors for your dedication to the Edmonton Walk to End ALS. The ALS Society of Alberta would also like to thank the 2019 Edmonton Walk to End ALS planning committee for the countless hours they dedicated to planning this incredible event. The Edmonton Walk raised over \$303,000. It is incredible to see the support pour in from the community, and to channel hope for a future without this devastating disease.



Drayton Valley

The second annual Drayton Valley Walk to End ALS took place on Saturday, June 15 in West Valley Lion's Park. Over \$32,000 was raised to support client services and research, which was an incredible achievement by a hard working group of volunteers and organizers. Thank you to Melanie, Nicole and Marcie for all of your work in the planning of this event and to all the volunteers and participants who came out to support the event. The ALS community is so excited to watch this event grow.



Cold Lake

The Cold Lake Walk to End ALS took place on Saturday, June 15 and raised \$9,000! Pat and Michelle Feduniak, along with their friends and family, have been dedicated volunteers and supporters of the ALS Society for many years. Without their unwavering support, the Cold Lake Walk to End ALS would not be possible. Thank you to everyone who participated!



Red Deer

The 16th Annual Red Deer Walk to End ALS was held on June 15 in Kiwanis Picnic Park. This year, over \$77,000 was raised to support client services and research. Thank you to the Red Deer Walk planning committee for all of your hard work in planning this event and to everyone who donated, participated, sponsored and volunteered to help make this event a great success.



Fort McMurray

The fourth annual Fort McMurray Walk to End ALS took place in Birchwood Trails on Sunday, June 16. Walk Coordinators, Paul Downey and Stephanie Williams worked hard in their community to raise funds and awareness for ALS. This year, over \$8,300 was raised! Thank you to everyone who sponsored, donated, volunteered and participated in the Fort McMurray Walk to End ALS!



Valley Ridge

The Valley Ridge Walk to End ALS raised \$2,530 this year. Thank you to the Valley Ridge Family Physicians for organizing this incredible event and to everyone who participated to help make this annual Walk such a success.



Hinton

It was an incredible morning at the 9th annual Hinton Walk to End ALS, with a record-breaking turnout of 115 participants, and raising over \$20,000! Sandi Rasmussen-Connolly and Beth McCallum worked tirelessly to support the ALS cause in the Hinton community, and has raised a great deal of awareness to help fight against the disease. Thank you for all that you do!



Peace District

The Peace District Walk to End ALS had another fantastic year, raising \$5,600 and counting! The Walk took place on Thursday, June 20 at Riverfront Park with support from volunteers, participants and donors. Thank you to Johanna Downing, her family and friends, as they continue to raise awareness in the Peace District and beyond.



Camrose

The Camrose Walk to End ALS took place in Mirror Lake Park on June 23. Over \$21,000 was raised thanks to the dedication and support from Cheryl & Lauren Feth and the Camrose ALS Community. Thank you to all who attended to help raise awareness, and for those who volunteered their time. The Society could not do what it does without the support of the Walk to End ALS Community!



Donations to The Walk to End ALS and Betty's Run for ALS

Did you know that you can still donate to The Walk to End ALS and Betty's Run for ALS? Donations for these events can be made up until December 2019. If you missed the event but still want to make a donation please visit www.alsab.ca and choose the event or contact Marni@alsab.ca to find out more. Your support is greatly appreciated!

Upcoming Events



For more information on events contact Marni@alsab.ca

Lethbridge Walk to End ALS September 7, 2019

Henderson Horseshoe Area Registration: 10 a.m. Kick-off: 11 a.m.

Calgary Parrot Head Club's Charity Golf Tournament Generously sponsored by Tops Pizza and Steak House September 7, 2019

Fox Hollow Golf Course (999 32 Ave NE, Calgary)
Registration starts at 2:30 pm / first tee off at 3:30 pm
\$65 for members / \$75 for non-members
Includes 9 holes of golf, power cart, dinner, competition holes, gifts and much more.

All proceeds will be donated to the ALS Society of Alberta For information or to register please contact: calgaryparrotheadclub@gmail.com

Songs for Ken

September 26 - Empress Theatre (Fort Macleod) September 27 - Southwood United Church (10690 Elbow Dr. SW, Calgary)

Songs for Ken is an annual concert-fundraiser in support of the ALS Society of Alberta. Created by John Wort Hannam, this event brings the Alberta folk music community together for two evenings of memories, music and fun. Funds raised will be donated to the ALS Society of Alberta.

Shaw Birdies for Kids

Shaw Birdies for Kids presented by Altalink is a fundraising program designated to give charities the opportunity to solicit donations and receive additional funding of up to 50%. Charities receive 100% of every donation collected on their behalf, as the Shaw Charity Classic covers all administrative costs to donate

The ALS Society of Alberta is honoured to be one of the charities chosen to participate in the program. If you make your donation to the ALS Society of Alberta, through the Birdies for Kids program, your donation will be matched up to 50%. This is a fantastic program to make your donation grow. Donations must be made by September 1, 2019 to be part of the program. To make your donation please visit www.shawcharityclassic.com/donatenow and choose The ALS Society of Alberta. For further information on the program contact Marni at Marni@alsab.ca.



Board of Directors

The ALS Society of Alberta's Annual General Meeting was held on May 28, 2019. We are happy to announce the 2019/2020 Board of Directors.

Tara Pentney Gord Banting Kimberly Howard

Chair Treasurer Director

Nancy Lyzaniwski Heather Haddow Karen Caughey
Vice Chair Director Executive Director

Jim Robinson Cathy Martin Secretary Director

Our Board of Directors dedicate their time and energy to the ALS Society of Alberta and we thank them for all that they do for the organization and our families.

Research Update

EDMONTON

There are more investigational drug trials than ever before for the treatment of ALS. The ALS Clinic in Edmonton offers many avenues to participate in research. The clinic is actively recruiting for multiple clinical trials. Dr. Wendy Jonhston, Clinic Director, is directing two main areas of research, Communications and Information seeking in people affected by ALS and investigational drug trials.

CALSNIC

Currently there is no test for ALS. Whereas, many other disorders are diagnosed with a simple blood test, x-ray or CT, the diagnosis of ALS is made in large part by ruling out other diseases that can mimic it. It is not uncommon that a patient has waited over a year for the diagnosis to be secured. Without a test that can objectively measure how much a patient with ALS is affected also delays the testing and discovery of new drugs.

The Canadian ALS Neuroimaging Consortium (CALSNIC) was formed to create and evaluate new tests for ALS that use advanced MRI. CALSNIC has 7 participating sites in Canada, and has recently branched internationally to include 2 sites in the USA. Over 170 patients and 130 health subjects have been enrolled from ALS clinics thus far. There have been a number of publications and presentations arising from CALSNIC. Most recently, Dr. Kalra and his team updated the international community at the ALSMND Symposium in Glasgow last December, at the ALS Canada Research Forum in Toronto in April, and at the American Academy of Neurology in May.

The CALSNIC team thanks patients, their caregivers, and friends and family who have given so generously of their time to be participants in the study. The study continues for another 2 years.

CAPTURE ALS

The Comprehensive Analysis Platform To Understand, Remedy, and Eliminate (CAPTURE) ALS is an initiative by Canadian investigators that will extend CALSNIC to include collection of blood, CSF, and post-mortem tissue. Such a biobank would be a critical resource for researchers to understand basic mechanisms and develop new diagnostic tests towards improving our understanding of ALs and finding effective treatment

CALGARY

There are three current ALS studies happening now and recruiting for all three.

MALLINCKRODT ACTHAR PENNANT STUDY

A MULTICENTRE, DOUBLE BLIND, PLACEBO CONTROLLED STUDY TO ASSESS THE EFFICACY AND SAFETY OF H.P. ACTHAR GEL IN THE TREATMENT OF SUBJECTS WITH AMYOTROPHIC LATERAL SCLEROSIS

Acthar is a prescription drug approved in Canada by Health Canada for use in some diseases such as systemic lupus erythematosus (SLE). It has also been approved in the USA by the Food and Drug Administration (FDA) called H.P. Acthar® Gel (Repository Corticotropin Injection, for the use in some diseased such as systemic lupus erythematosus (SLE). It has not been approved by regulatory authorities for ALS.

This study is being conducted to determine if Acthar will help patients with ALS by either slowing down how fast ALS symptom progress and/or increasing life expectancy.

PIMOZIDE 2 STUDY

A PHASE II RANDOMIZED, PLACEBO-CONTROLLED, DOUBLE-BLINDED, MULTI-CENTRE CLINICAL TRIAL OF PIMOZIDE IN PATIENTS WITH AMYOTROPHIC LATERAL SCLEROSIS

Pimozide is a neuroleptic medication that is approved by Health Canada and the FDA to treat chronic psychosis, Tourette Syndrome, and resistant tics. This study will look at whether Pimozide may help to slow the progression of ALS through this mechanism.

ORION "REFALS" LEVOSIMENDAN

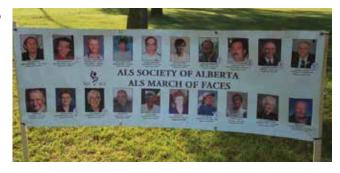
EFFECTS OF ORAL LEVOSIMENDAN (ODM-109) ON RESPIRATORY FUNCTION IN PATIENTS WITH ALS Levosimendan (Simadax®) is a FDA approved medication given through the vein for heart failure. It is not approved for use in Canada currently for either heart failure or ALS. In this study, the same substance will be tested for ALS given as a capsule taken via the mouth. Levosimendan (ODM-109) is an investigational medications, meaning that it has not been approved by regulatory authorities for ALS.

The main purpose of this research study is to measure how well and how safe Levosimendan (ODM-109) is in treating patients with ALS. This will be done by measuring breathing function. Animal studies have shown it may be useful to improve the muscle strength of the diaphragm and thereby the breathing function for patients with ALs

For information on these studies please phone Janet Petrillo at (403)210-7006.

Faces of ALS Banners

Would you or your loved one with ALS like to be recognized on our Faces of ALS Banners? These banners are displayed at events such as the Walks and Betty's Run. To find out more about the Faces of ALS banner or to make arrangements please call (403)228-3857.



SUPPORT GROUPS

All support groups and information sessions are provided free of charge. They are offered in casual group settings that provide everyone with an opportunity to share their experiences, information and support. Please note that the groups may be cancelled due to inclement weather be sure to take down the contact information below.

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 warm and casual 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

For people living with and affected by PLS, Kennedy's and other neuromuscular disorders.

Calgary

ALS Support Group

Dates: July 11 Time: 1 p.m. - 3 p.m.

Place: Bridgeland Riverside Community Association, 917

Centre Ave NE

Contact: 403-815-1567 | Rob@alsab.ca

ALS Family & Spousal Support Group

Dates: July 29, Aug 26 Time: 1 p.m. - 3 p.m.

Place: Quarry Park Library, Room #2

108 Quarry Park Road SE

Contact: 403-815-1567 | Rob@alsab.ca

Staying in Touch

Dates: Aug. 12, Oct. 7, Dec. 2
Time: 6:30 p.m. - 8:30 p.m.
Place: ALS Society Calgary Office
Contact: 403-815-1567 | Rob@alsab.ca

PLS & Kennedy's Group

Dates: July 29, Aug 26 Time: 1 p.m. - 3 p.m.

Place: North Hill Mall Condo Complex | 1718 14 Ave NW

Contact: 403-620-1358 | Leslie@alsab.ca

Edmonton

ALS Support Group

Dates: Jul.16, Aug.20 Time: 1:30 p.m. - 3 p.m.

Place: ALS Society Edmonton Office

Contact: 780-487-0754 | SocietyNorth@alsab.ca

ALS Family & Spousal Support Group

Dates: Jul.16, Aug.20 Time: 1:30 p.m. - 3 p.m.

Place: ALS Society Edmonton Office

Contact: 780-487-0754 | SocietyNorth@alsab.ca

PLS & Kennedy's Group

Dates: Jul.19, Aug.16 Time: 2 p.m. - 3:30 p.m.

Place: ALS Society Edmonton Office

Contact: 780-487-0754 | SocietyNorth@alsab.ca

Staying in Touch

Dates: Jul.19, Sept. 20, Nov. 15 Time: 11:30 a.m. - 1 p.m.

Place: ALS Society Edmonton Office

Contact: 780-487-0754 | SocietyNorth@alsab.ca

St. Albert

ALS & PLS Group

Dates: Jul. 5

Time: 2 p.m. - 3:30 p.m.

Place: Servus Credit Union Place, Morinville Room Contact: 780-487-0754 | SocietyNorth@alsab.ca

Lethbridge

ALS Support Group

Dates: Jun. 28, July 26, Aug. 30

Time: 2 - 3:30 p.m.

Place: Nord-Bridge Seniors Centre Contact: 403-620-1358 | Leslie@alsab.ca

Red Deer

ALS Support, Family & Spousal Support Group

Dates: TBA Time: TBA Place: TBA

Contact: 403-815-1567 | Rob@alsab.ca

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

CONTACT US

PROVINCIAL OFFICE

7874 10 St NE Calgary, AB T2E 8W1 www.alsab.ca | info@alsab.ca (403) 228-3857 | Fax (403) 228-7752 Toll Free: 1-888-309-1111

EDMONTON OFFICE

5418 97 Street NW Edmonton, AB T6E 5C1 societynorth@alsab.ca (780) 487-0754 | Fax (780) 486-3604 Toll Free: 1-866-447-0754

PLEASE CONSIDER MAKING A MONTHLY GIFT

account at the beginning / middl OR charge my monthly donation of 9	e (circle) of each month. (Pleas to my credit card	donation of \$ from my bank se attach a blank cheque marked VOID). 3857 to set up credit card donations).
Date	Signature	
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 (<i>Please call (403)228-3857 to set up credit card donations</i>).		
Please send my charitable tax re	ceipt to:	
Last Name	First Name	
Address		
City/Town	Province	Postal Code
Phone	F-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.