

# Prairie to Peak

A PUBLICATION OF THE ALS SOCIETY OF ALBERTA

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## Making it Possible

Another hockey season has begun, and Mikael Backlund has continued to host our families at a game every month! Thank you Mikael for making these memories with the ALS community!



## Uncorked for ALS

On Friday November 10, the Calgary Flames Foundation hosted Uncorked for ALS, raising awareness and funds for ALS research. The fundraiser was inspired by Mikael Backlund and his fiancée Frida Engstrom, who lost her mom to ALS in Sweden. We are so fortunate to have the support of the Calgary Flames community.







## Giving Tuesday

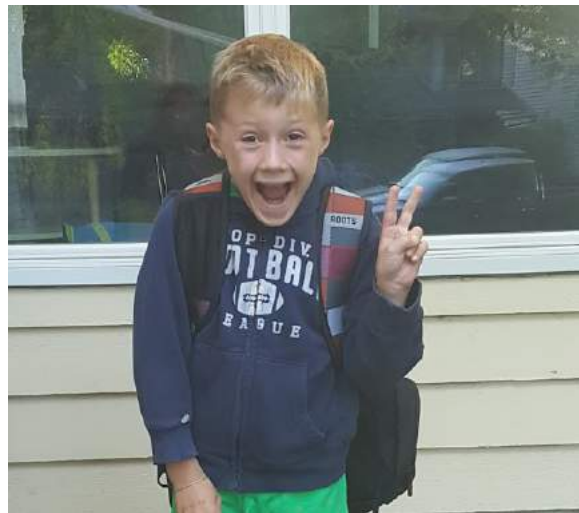
Most people know about Black Friday and Cyber Monday, but now Giving Tuesday has taken Canada by storm by encouraging a day of charitable giving. November 28 marked the 2017 Giving Tuesday, and the ALS Society of Alberta celebrated by raising funds for the Support for Champions program. This program allows children whose parents are affected by ALS to participate in childhood activities that may not be available to them due to the immense financial burden of ALS.

“

My son, Owen, received money for his basketball season this year from the Support for Champions program. His father has been living with ALS for the past five years. Owen loves playing basketball, skiing, biking, snowboarding and playing video games. When he is visiting his dad, he makes paper airplanes to hang in his room. He is a creative, active and loving seven-year-old and we thank the Support for Champions program for giving him the opportunity to play basketball this year.

*Support for Champions Recipient*

”



The need for this type of support is real and is currently not being met for some families in Alberta. Many families do not have the financial means and social network to be able to ensure that the children affected by ALS are able to engage in social activities, process their grief, enjoy childhood and look forward to a bright and promising future. For some families there is a struggle in balancing financial responsibilities and recreational activities, a struggle that the Support for Champions program aims to help.

With an initial fundraising goal of \$10,000, the Society was blown away when nearly \$12,000 was donated through Giving Tuesday. These contributions will make a significant impact in the lives of children and youth affected by ALS, and the Society would like to thank each and every donor that pledged their support through Giving Tuesday!

# An Evening of Appreciation...

On November 8, the Alberta ALS community gathered to celebrate the incredible achievements of volunteers and staff in 2017. Celebrations occurred in both Calgary and Edmonton, and provincial awards were given to a number of the Society's volunteers and supporters. Thank you to everyone who joined us in recognizing these achievements.



**Norman Pollock - Exceptional Volunteer Award**  
Ashley de Nooij

The Norman Pollock Exceptional Volunteer Award aims to recognize exemplary volunteer leadership and is given to an individual who epitomizes volunteerism through selfless contribution to the ALS community and those it serves. The Society was proud to present Ashley de Nooij with this year's award. Ashley is a dedicated, talented and long-term volunteer for Betty's Run for ALS. Thank you for your unwavering commitment to the ALS cause, Ashley.



**Honourary Life Member and 15 Years of Service**  
Jan Desrosiers

Jan first joined the ALS Society's Board of Directors in 2002. Jan has been a driving force behind the ALS Society, fulfilling many roles and most recently the Chair of the Board of Directors and the Alberta representative on the ALS Societies Across Canada's Federation Council. Jan has dedicated her life to ALS and to making a difference for families in Alberta. Thank you for all that you do for the ALS cause, Jan, and congratulations on your achievement!



**Proud Supporter**  
Brenda Davidson

Brenda has been a long-term supporter of the Society and the ALS community. Having known colleagues and friends affected by ALS, Brenda has taken it upon herself to raise awareness about the ALS cause and provide support for many different fundraisers. Thank you, Brenda!



**WALK for ALS Award**  
Hinton WALK for ALS

The Hinton WALK for ALS is truly more than a one-day event. This dedicated group of volunteers led by Deena Fuller and Sandi Rasmussen-Connolly work hard to "paint the town purple" leading up to the event, and generate an incredible amount of awareness in the Hinton area. Thank you, Hinton!





### WALK for ALS Award

James and Jeanie Brown

James and Jeanie Brown graciously joined the WALK for ALS family in 2015, and have made a tremendous impact in Edmonton. In 2016, they began the first-ever Edmonton WALK for ALS Team Challenge. Over the past several years, the WALK has grown tremendously, now raising over \$400,000 and bringing together over 1,100 members of the Alberta ALS Community. Thank you James and Jeanie for your unwavering commitment to the ALS cause!



### Exceptional Fundraising Program Award

Lloydminster Firefighters

Over the past five years, the Lloydminster Fire Department has selflessly dedicated a chilly 48 hours in November to ALS fundraising and awareness. Despite often blistering weather conditions, the department camps out on the rooftop of the fire hall for an entire weekend, which has now raised over \$124,000 for the ALS Society! Thank you to Chief Newton and the rest of the fire department for all of your hard work and support!



### Exceptional Public Awareness Program Award

Reid Larsen and Ricky Lam

The Exceptional Public Awareness Program Award recognizes and celebrates exceptional programs that have educated and increased public awareness. It was our privilege to honour Reid Larsen and Ricky Lam with this award. We first met Reid and Ricky in early 2015, when they presented us with an exceptional plan for two different PSAs. Despite the agency that they worked for closing its doors in 2016, Reid and Ricky continued to dedicate their time to the Society's awareness initiatives, completing both PSAs that have championed the Society's mission of "Making it Possible" to make each day the best possible day for people living with and affected by ALS.



### Making Possibilities

Mikael Backlund and Frida Engstrom

In the fall 2014, Frida and Mikael asked the Society how they could get involved. Since 2015, Mikael and Frida have hosted more than 37 families at the Calgary Flames games. They provide front row tickets for our families to have a night out together and at the end of the game, Mikael makes time to meet each family and give them an autographed jersey. In addition, Mikael donates \$200 for each point he makes and the Calgary Flames Foundation matches his donation. Frida also hosted an Ice Bucket Challenge auction last year, raising over \$5,000 for our client services and support. Thank you Mikael and Frida for all that you do!



### Exceptional Fundraising Program Award

John Wort Hannam

John had a vision to host a unique event to bring his friends, family and the community together in honour of his childhood friend, Ken Rouleau. In 2015, Songs for Ken came to life. The first concert was held in the beautiful Empress Theatre in Fort Macleod. John brought his colleagues and friends together from the arts community and sold out his first concert. He has now raised more nearly \$27,000 to support families in Alberta. Thank you for your dedication, John.



### Exceptional Fundraising Program Award

Saz's Soldiers

Tanya Sasyniuk and her family have been a tremendous support to the ALS Society of Alberta. For the past six years, they have hosted a golf tournament annually in Beaumont that has raised funds and awareness about ALS in Alberta. In honour of her husband, Derek, Tanya and her beautiful two young daughters have worked hard to help fight Derek's battle with ALS. Thank you to the Sasyniuk family for your unwavering commitment to the ALS cause!

## Special Acknowledgements...

### Ryan Caughey and Vince Raquel

In the spring of 2017, Ryan and Vince selflessly donated their time and skillset to develop a video about the Society's Equipment Loan Program. Vince and Ryan did an incredible job, delivering us a polished, professional video in just a matter of days. The video has now been seen over 15,000 times by members of the ALS community, and has been an incredible method for raising awareness about the Society. Thank you, Vince and Ryan!

### The Board of Directors

The Board of Directors are the foundation of the ALS Society. They are ten amazing leaders that consistently give of their time and expertise to the Society, all on a voluntary basis. Each person brings amazing skills and expertise but more importantly they bring passion to the cause. Combined they have contributed more than 99 years of service to the ALS cause. We also recognized two retiring Board members, Jim McLaughlin and Chris White for their incredible contributions over the years.

### Long-term Service

Brandee Fossen - Five years

Brandee first joined the Society as the WALK Coordinator in Camrose, and then joined the Society's team of staff, now filling the role of the Manager of the North Region. Brandee is dedicated, compassionate and goes over and above her role to ensure our families' needs are met. Thank you, Brandee!

### Long-term Service

Dave Williams - Ten years

Dave first joined the Board in 2007. He has guided the Society through its amazing growth over the past ten years. He gives so much to the Society to truly make a difference for people living with ALS. Thank you Dave for your amazing leadership and commitment to our ALS families.

# ALS Client Services Conference

November 14 - 16, 2017



**Building strength, support and capacity across Canada with our client services so we can provide the best possible support for people living with and affected by ALS.**

The first-ever client services conference for the ALS Societies across Canada was hosted in Alberta. This three-day conference offered the Societies' client support staff to discuss best practices of ALS support and advocacy while providing an opportunity for self-care and wellness.

Hosted at the Banff Centre, the conference began with a discussion of the different programs and services offered across Canada for people living with and affected by ALS. Staff discussed innovative solutions for client support, and shared the practices of each province. The conference was grateful to have Frida Engstrom present about the support services available in Sweden, and how Canada is leading the charge in support for those affected by the disease.

Self-care and coping strategies were the focus of the second day. Dr. Douglas Cave of the Centre for Practitioner Renewal joined the conference to develop an understanding of coping strategies for those supporting people living with ALS, including both staff and caregivers.

The final day of the conference gave the Societies' an opportunity to refine their advocacy skills and participate in case studies related to the provision of care for those affected by ALS. Open Arms Advocacy joined the conference to discuss advocacy at an individual and community level, including engagement with health and social service organizations, politicians, and government.

The ALS Societies across Canada would like to thank each and every speaker, participant and volunteer that helped make this conference such a success. By bringing Canada's ALS support staff together, opportunities for collaboration and program enhancement can occur to help make a stronger impact in the lives of those affected by this disease.

The Societies are so grateful for the outstanding skill and resilience that its client support staff possess, and are sure that they will continue to empower the ALS community for years to come.



## Community Events

### ▼ Gerard Thom ALS Fundraiser 2017

A fantastic group of hardworking fundraisers in Lethbridge helped raise awareness and funds for the ALS Society of Alberta in August! Thank you so much to Mint Smartwash and the Thom family for making this possible.



### ▼ Around Canada in 18 Holes

The Boilermakers Union Local 146 held their “Around Canada in 18 holes” golf tournament on August 19 where the ALS Society of Alberta was the charity of choice. Everyone had to putt with a goalie stick on the Society’s “Putt like a Canadian hole.” Over \$5,000 was raised!



### ◀ Howard Smith Memorial ALS Roping

The ALS Society of Alberta would like to send a big thank you to the Howard Smith Memorial ALS Roping event for its continued support of the Society! This event is one of our longest-running community fundraisers, and we are so grateful for the dedication! This year’s event took place on August 20.



### ◀ Nancy McLennan Memorial Golf Tournament

The first annual Nancy McLennan Memorial Golf Tournament raised approximately \$10,000 for the ALS Society of Alberta! It was an incredible success for its first-year running, and is hoping to hold the second annual in June, 2018! Thank you to Michelle Barry for all of your hard work in organizing this event.



### ◀ Saz’s Soliders ALS Charity Golf

The sixth annual Saz’s Soliders ALS Charity Golf Tournament was another amazing success and the Society was honoured to attend. This year’s event brought in \$10,000 for client support services in Alberta. Thank you to the Sasyniuk family for all that you do!



## ▼ Moro Memorial Ride

The second annual Moro Memorial Ride took place at YYC Cycle on October 14. The studio graciously donates three classes to the ALS Society of Alberta, encouraging participants to donate and raise awareness about the cause. In memory of her mother, Payton Moro worked hard to organize a silent auction and fundraising website that raised over \$8,700 for the ALS Society of Alberta. Thank you to the spin instructors at YYC Cycle for your support, and to the Moro family for all that you do!



## ▼ Big Drew's Big Ride

The annual Big Drew's Big Ride raised over \$9,000 for the Society this year! With an initial fundraising goal of \$4,000, it is clear that the support in Drew's honour will always live on. Thank you to all donors, and to Jim Robinson for your continued coordination of this event!



## ▲ Skip Hayden Memorial Golf Tournament

The Skip Hayden Memorial Golf Tournament took place on August 25 in Olds! This was the first year that the tournament partnered with the Society to raise awareness and funds through a 50/50 draw. Thank you to the Alberta Association of Recreation Facility Personnel!

## ▼ Judy Schweitzer ALS Curl for a Cure

The eighth annual Judy Schweitzer ALS Curl for a Cure took place on Saturday, November 11 in Red Deer! The event was another huge success, with an incredible prize draw and a great deal of awareness raised for the Society. Thank you to Carrie Mello, and all of her friends and family that help to make this event happen each year. Carrie began the Funspeil in honour of her mother, Judy, in 2010 and has been an exceptional support for the Society ever since!



## ◀ Bouge's Buds

The Debogorski family in Yellowknife held their first-ever Bouge's Buds fundraiser in honour of Andrew who is living with ALS. They graciously donated 10 per cent of all proceeds to the ALS Society of Alberta, which came out to an incredible \$3,500! The Society is so grateful for all of the support and awareness that the Debogorski family continues to raise in the Yellowknife area, and wish them the sincerest of congratulations for such a successful fundraiser!

## ▼ Lloydminster Fire Department ALS Rooftop Campout

From November 24 – 26, the Lloydminster Fire Department camped on the roof of the fire hall in support of the ALS Society of Alberta. This year's event raised nearly \$29,000 for the Society, making it one of the largest community fundraisers in the province. Thank you to Chief Newton and the rest of the fire department for the consistent support, and for the awareness raised in the Lloydminster area!



## ▼ Phi Delta Theta 24-hour Teeter Totter Marathon for ALS

The Phi Delta Theta Fraternity at the University of Alberta hosted the annual 24-hour teeter totter marathon for ALS in early October. This event has raised a great deal of awareness among the university community since its inception, and raised over \$6,000 this year! Thank you to Rene and the rest of the fraternity for your hard work!



## WALK for ALS



### Lethbridge

The Lethbridge WALK for ALS has been championed by the Thom Family over the past two years. It all began when Gerard Thom selflessly donated his time and efforts to spread awareness about ALS, and act as the Ambassador for the 2016 Lethbridge WALK. The Thoms now continue to pursue unique initiatives in Lethbridge in support of the ALS Society of Alberta. Thank you to Shelley, Adam and their friends and family for the incredible WALK this year!



### Hinton

The Hinton WALK for ALS painted the town purple again this year and raised over \$19,000 for the ALS Society of Alberta. Thank you to Deena Fuller, Sandi Rasmussen-Connolly, and the rest of the Hinton WALK for ALS volunteers! It has been incredible to watch the WALK grow and to see all of the support in the Hinton area.



# 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.

## NEUROMUSCULAR DISORDER SUPPORT GROUP

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

## YOUTH GROUP

For youth who have a parent or relative who has been affected by ALS.

## Calgary

### ALS Support Group

Dates: Jan. 6, Feb. 10  
Time: 1:30 - 3:30 p.m.  
Place: ALS Society Calgary Office  
Contact: 403-714-8211 | Jane@alsab.ca

### ALS Family & Spousal Support Group

Dates: Dec. 12  
Time: 6:30 - 8:30 p.m.  
Place: 8211 Churchill Drive SW  
Contact: 403-714-8211 | Jane@alsab.ca

### Staying in Touch

Dates: Feb. 5  
Time: 6:30 - 8:30 p.m.  
Place: ALS Society Provincial Office  
Contact: 403-620-1358 | Rob@alsab.ca

### Neuromuscular Disorder Support Group

Dates: Jan. 29, Feb. 26  
Time: 1 - 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: Dec. 19, Jan. 16, Feb. 20, March 20  
Time: 1:30 - 3 p.m.  
Place: ALS Society Edmonton Office  
Contact: 780-487-0754 | SocietyNorth@alsab.ca

### ALS Family & Spousal Support Group

Dates: Dec. 19, Jan. 16, Feb. 20, March 20  
Time: 1:30 - 3 p.m.  
Place: ALS Society Edmonton Office  
Contact: 780-487-0754 | SocietyNorth@alsab.ca

### Neuromuscular Disorder Support Group

Dates: Dec. 15, Jan. 19, Feb. 16, March 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: Jan. 19, March 16  
Time: 11:30 a.m. - 1 p.m.  
Place: ALS Society Edmonton Office  
Contact: 780-487-0754 | SocietyNorth@alsab.ca

## Lloydminster

### ALS Coffee Group

Dates: TBA  
Time: 1 p.m.  
Place: Atrium Centre, Basement  
5010 49 Street, Lloydminster  
Contact: 780-487-0754 | SocietyNorth@alsab.ca

## St. Albert

### ALS and PLS Group

Dates: Jan. 5, Feb. 2, March 2  
Time: 2 - 3:30 p.m.  
Place: Servus Credit Union Place  
Morinville Room  
Contact: 780-487-0754 | SocietyNorth@alsab.ca

## Lethbridge

### ALS Support Group

Dates: Last Friday of the month  
Time: 2 - 3:30 p.m.  
Place: Nord-Bridge Seniors Centre  
Contact: 403-620-1358 | Leslie@alsab.ca

### \*Session Hosted by South Health Campus\*

#### Nutrition and Swallowing Difficulty

Date: March 6  
Time: 1 - 2: p.m.  
Classes will focus on food textures and easy to prepare nutritious foods to meet protein and calorie needs.  
Call Debbi at 403-956-1485 to register.

## Research update

The results of the 2017 funding competition for Canadian ALS research was announced in November. Twelve exciting projects were chosen, including a multi-year study of a promising drug combination, three trainee grants that will help to nurture the next generation of Canadian ALS researchers currently pursuing their PhDs, two projects that will explore how ALS treatments could be delivered through the bloodstream, and an initiative that seeks to understand why the muscles of the eyes are often more resilient to ALS as other muscle groups shut down.

These projects were made possible by the contributions from the ALS Societies across Canada and matching funds by Brain Canada, including the 40 per cent of proceeds dedicated from the WALK for ALS and Betty's Run for ALS.

The research being funded in 2017 seeks to answer the following questions that will help to move us from greater understanding of ALS to the development of therapies for human use:

- Can adjusting the levels of a “guardian” protein protect a protein that becomes toxic in most cases of ALS? \$125,000 awarded to Dr. Marco Prado with collaborators Dr. Martin Duennwald and Dr. Flavio Beraldo, all from Western University
- Can image-guided focused ultrasound technology be used safely in people living with ALS as a means of delivering future treatment? \$124,948 awarded to Dr. Lorne Zinman with collaborators Dr. Nir Lipsman, Dr. Kullervo Hynynen, Dr. Sandra Black, Dr. Todd Mainprize, and Dr. Agessandro Abrahao, all from the University of Toronto
- Can microscopic bubbles in our bodies be used to deliver ALS treatments through the bloodstream? \$125,000 awarded to Dr. Derrick Gibbings with collaborators Dr. Baptiste Lacoste and Dr. Maxim Berezovski, all from the University of Ottawa
- Could targeting the activity of motor neurons in the spinal cord be a new way to diagnose and treat ALS? \$125,000 awarded to Dr. Yves De Koninck, Université Laval
- Could the change in communication processes between motor neurons and the immune cells of the nervous system after an ALS diagnosis help to identify new treatment targets? \$124,930 awarded to Dr. Stefano Stifani, McGill University
- Could touchscreen technology help to improve testing for the cognitive impairment that occurs in some cases of ALS? \$110,770 awarded to Dr. Flavio Beraldo with collaborators Dr. Marco Prado and Dr. Vania Prado, all from Western University
- Could whole genome sequencing reveal new areas of genetic mutations that make some people more likely to develop ALS? \$75,000 awarded to Jay Ross, a PhD student in Dr. Guy Rouleau's lab at McGill University
- How might misfolded proteins that occur in ALS cause cells to die? \$50,000 awarded to Sonja Di Gregorio, a PhD student in Dr. Martin Duennwald's lab at Western University
- What can we learn from mice that are able to walk almost normally despite significant loss of motor neuron function? \$125,000 awarded to Dr. Turgay Akay, Dalhousie University
- Why are eye muscles more resistant to ALS, and what can we learn about this that could help to preserve the function and use of other muscles? \$121,048 awarded to Dr. Richard Robitaille with collaborator Danielle Arbour, both from Université de Montréal
- Will probiotics that improve ALS symptoms in worms also work in mice? \$75,000 awarded to Audrey Labarre, a PhD student in Alex Parker's lab at the Université de Montréal





There are many different ways that you and your family can support the ALS Society of Alberta this holiday season. Your support and donations help to make each day the best possible day for people living with and affected by ALS in Alberta, and make a direct impact within the community.



#### **Become a monthly donor**

You determine the amount of your monthly gift that will make a significant difference within the ALS community. You can adjust your pledge at any time, and each year you will receive an annual giving statement that you can use for your income tax.



#### **Make a donation in honour or in memory of an individual**

You can support a loved one by making a donation in their memory or in their honour. The family will receive a card informing them of your donation, which makes for a thoughtful and impactful holiday gift for a family who is affected by ALS.



#### **Host a community event**

The holidays are a great time to gather with your friends and family and do some fundraising. Whether its a gingerbread house competition, silent auction, or a night of fun at the bowling alley, there are many ways to incorporate ALS fundraising. If you have an idea for an event, contact [Lisa@alsab.ca](mailto:Lisa@alsab.ca).



#### **Planned giving**

As part of your long-term financial planning, a planned gift can offer substantial tax and estate planning benefits and allow you to make a larger and longer-lasting gift to the ALS Society of Alberta. Donations can be made through a bequest in your will, gifts of securities, registered assets (RRSP and RRIF) and gifts of life insurance. Contact the Society for more information at [info@alsab.ca](mailto:info@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

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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

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## PLEASE CONSIDER MAKING A MONTHLY GIFT

I authorize the ALS Society of Alberta to withdraw my monthly donation of \$\_\_\_\_\_ from my bank account at the beginning / middle (circle) of each month. (Please attach a blank cheque marked VOID).

OR

I authorize the ALS Society of Alberta to charge my monthly donation of \$\_\_\_\_\_ to my credit card at the beginning / middle (circle) of each month. (Fill out credit card information below).

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 (Fill out credit card information below).

Please send my charitable tax receipt to:

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

Address \_\_\_\_\_

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

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

Credit Card Information:

Select:    Visa                    MasterCard                    American Express

Credit Card Number \_\_\_\_\_

Expiry Date \_\_\_\_\_ CVV# (3 digit located on back of card) \_\_\_\_\_

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.*