Volume 10, Issue 1



ALS Society of Alberta



ALS Society of Alberta Mission Statement

"The Amyotrophic Lateral Sclerosis Society of Alberta is dedicated to making everyday the best possible day for people affected by ALS by providing support, facilitating the provision of care, promoting awareness, helping find a cure and advocating for change."

ALS Society of Alberta

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Interested in volunteering for the ALS Society of Alberta?

Please call Stephanie at 403-228-3857 or email Stephanie@alsab.ca.

Highlights from Research Breakthroughs in 2011 A Landmark Year in the History of ALS Research

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While advances in ALS research over the past three years have been outstanding, 2011 was a year of multiple exciting breakthroughs many are calling a true turning point for ALS research worldwide. These new findings build on steady advances in fields as diverse as biomarkers (substances which indicate a biological state); the extraction and use of stem cells to potentially restore function; advanced imaging techniques; the role of environmental toxins and genetic sensitivies; and complex cell biology.

With these new 2011 findings, we have many more pieces of the puzzle – pieces with the potential to enable earlier detection, faster halting of symptoms, better drugs and treatments and – with more investigation – the possibility of partially restoring damaged neural pathways.

July 2011 - Sanjay Kalra, MD, University of Alberta

Dr. Sanjay Kalra from University of Alberta's Faculty of Medicine and Dentistry released two studies that used advanced imaging to show that ALS attacks multiple parts of the brain and is not limited, as previously assumed, to the motor system. Dr. Kalra used MRI scans to detect chemical changes that indicate specifically which neurons are not working or have died – a landmark breakthrough in our ability to identify the locus, onset, and ontology of the disease. These advances have significant potential to track ALS and its progression, enabling development of more targeted treatments to slow or prevent the disease in those parts of the brain which are affected beyond the motor system.

September 2011 - Neil Cashman, MD, University of British Columbia

In healthy individuals, special enzymes protect cells from dangerous free radicals. But malformed enzymes, such as those found in ALS, may have the opposite effect, in essence initiating damage rather than protecting against attack by dangerous free radicals, in a twisted game of molecular tag. Dr. Neil Cashman and colleagues at the University of British Columbia reported in 2011 on their use of a truncated enzyme and special antibodies to analyze the folding and misfolding of a key protein. The goal is to create new proteins with a special binding capacity to act as a "sticky patch" where "bad" enzymes can attach and be removed from the system. With further development, these proteins have the potential to block unhealthy interactions, thereby stopping disease progression in its tracks.

These are just a few of the most recent breakthroughs. To read the full article, or more on Canadian ALS Research, visit www.als.ca and click on the Research tab.

Canadian Neuromuscular Disease Registry

The Canadian Neuromuscular Disease Registry (CNDR) is a national database of patients who have been diagnosed with a neuromuscular disease. Launched in June 2011, the CNDR is a clinic-based registry and information is collected from patients during regular clinic visits at their neuromuscular clinic. Joining the registry is completely voluntary and has no cost.

Patients who are not attending a participating clinic can register themselves by contacting the CNDR National Office at I-877-401-4494 or by emailing admin@cndr.org. The CNDR National Office is located at the University of Calgary.

As of December 31, 2011 the CNDR had enrolled 562 patients. 16% of these patients have ALS. In mid-2012 the CNDR will be adding a comprehensive medical data collection module for patients who have ALS. This will allow researchers to access medical histories of ALS patients all across Canada; a very important step towards understanding the causes of the disease.

For more information please visit the CNDR website at www.cndr.org.

Submitted by the Canadian Neuromuscular Disease Registry

Familial Amyotrophic Lateral Sclerosis in Alberta

Ted Pfister, a graduate student in the Department of Community Health Sciences at the University of Calgary, has completed a review of all cases of familial ALS in Alberta over the past decade. This work, under the supervision of Drs. Lawrence Korngut and Sanjay Kalra from the Calgary and Edmonton ALS Clinics is shedding light on the frequency of familial ALS in Alberta and the types of genetic mutations that are responsible.

The study began due to a lack of available information about Familial ALS in Canada. Prior studies have examined the ALS in Alberta but did not distinguish between sporadic and familial cases.

A better understanding of Familial ALS in Alberta will establish what types of genetic mutations are common in Alberta and improve access for future Albertans with Familial ALS to clinical trials specifically designed for this uncommon form of ALS. This study will be wrapping up this year. For more information on this study, please contact Ted Pfister from the University of Calgary at trpfiste@ucalgary.ca or Dr. Lawrence Korngut through the University of Calgary ALS Clinic.

This study was made possible by a generous donation from the Quirk family.

Submitted by the University of Calgary ALS Clinic

Children's Corner

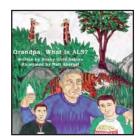
There are many resources available for children and youth who are affected by ALS. Here are a few:

411 Booklets

There are five different booklets, designed to help children and teens affected by ALS in their family.

- "Helping Children Cope with ALS A Parental Information Guide"
- "When Someone Special Has ALS A booklet for Children"
- "When Your Parent Has ALS A Booklet for Teens"
- "Talk With Young People About ALS For Schools"
- "Talking With Your Patient's Children About ALS A Primer for Health Professionals"

Grandpa, What is ALS Written by Bonny Gold-Babins, Illustrated by Matt Abergel



You can view both of these resources online at www.alsab.ca and click on the Family Resources link at the bottom of the page. You may also order hard copies from the ALS Society of Alberta. Contact our Provincial Office for more information.

In 2011, the ALS Society of Alberta supported 275 clients across the province, and lent out over 1,400 pieces of equipment from our Equipment Lending Program.

We are only able to support our clients because of people like you. Thank you for all of your support and generosity!

Tips and Tricks

"Mappin-It"

The ALS Society recently heard a great tip from Kathy, a family member affected by ALS and living in a rural area. She has made a coloured map of directions to her family's home with road markers, highway numbers, and their rural address emergency number and placed it on their refrigerator. This makes it easy for anyone such as a homecare workers and relatives in the house to access and relay this information to others should they need it in a hurry. Kathy also sent this map to the homecare office, the ALS clinic, and the ALS Society. We thought this was a good reminder for all of us regardless of where we live to keep important information like home addresses, directions, and emergency contacts readily available and easy to find.

Thanks for the tip Kathy! Submitted by Megan Blomfield

"Lotsa Helping Hands"

www.lotsahelpinghands.com

Founded by a personal family experience when a caregiver spouse became overwhelmed with offers of help. This resource brings together a variety of social circles, creates communities, and facilitates scheduling of offers to help with the tasks. This resource makes it easy for each person to know what to do to help, and when to do it.

Submitted by Patricia Ordynec



Travel Tips from Roger Brightwell

My inspiration to keep traveling came from Alper Kaya from Turkey. I read about him on the Patients Like Me website. He was diagnosed with ALS 23 years ago and was able to travel from Turkey, to Berlin, Germany for the ALS Conference in 2009 while on a trach. My thought was, if he can figure out travel, so can !!

The key thing to remember is everything is just a logistic, in the case of traveling with a disability the logistics include everything needed to travel and provide the support needed to go through your day. I would like to add it is not just your day, but the day of everyone in your group. Here are some of my tips:

- Be realistic of everyone's needs and expectations. For example, how many people is it going to take to carry luggage and equipment? Who is going to do it? Are they aware and do they agree to it?
- If you or anyone you are traveling with has any uncertainty about your or their health, see your/their doctor to be sure everyone is physically up for the trip.
- Ensure that there will be adequate health care facilities at your destination if the need arises.
- Make sure you are aware of what is and isn't covered under your Health Insurance.

Last summer my family of 6 traveled to Mexico and back by road! We traveled in two vehicles and stayed in pre-booked hotel rooms. When booking a hotel, you should considerbringing a list of your requirements (my requirements were wheelchair accessible and roll in shower). We traveled with a wheeled Commode Chair and portable freestanding Lift. The Commode Chair could come apart and fold up to a size comparable to an average size suitcase. We brought the freestanding lift as most hotel beds are a box type frame, which does not allow the wheels on a Hoyer style Lift to roll under the bed.

After the success of the road trip to Mexico, I decided to take on the skies. It took a lot of planning to come up with a workable plan, but I did it.

If you are considering a flight, here are some tips:

- Contact the airline you prefer to fly and ask to be referred to their medical desk (or the department for accessible access) and ask about the procedures, perks, and other issues you may have to deal with such as the time needed for various forms, booking of extra help needed from the airline, etc. Try to have a computer handy you may be directed to forms on the airline website.
- Check to see if there any reductions in fare for the caregiver and what the procedure is to apply for it, some airlines offer a free or discounted seat for caregivers.
- If you have cushion on your wheelchair (like a Roho), grab it to sit on for a more enjoyable flight.
- Any tools that are needed to disassemble the chair to make it into the allowable dimensions (removing headrest) have to be supplied by you. Keep them in your carry-on luggage and pack a spare tool in case the first one gets lost by airline staff.
- The allowable dimensions for your chair are determined by the size of the cargo door on the plane.

Continued on Page 4

Another challenge I had to deal with was my bipap machine. I was instructed by my doctor to use my bipap in flight if necessary. I bought a 12 volt cord (available at Respiratory Home Care) then I took the cord and machine to Battery World (the store's specialty is batteries for every application). They calculated the electrical draw and sold me a battery that should run the bipap machine without the humidifier for 5 hours.

The best resources are the ALS Societies (in Canada) and the ALS Association (in the US). The ALS Association of Phoenix put me in contact with people for all my equipment needs. I arranged to rent an accessible Van, Hoyer Lift and a Power Wheelchair. The logistics of traveling can be dealt with, with a little thought and planning. I hope this gives everyone an idea of the possibilities of travel with a disability. My view is this disease shortens our lives but it is up to us to make our lives as enjoyable as possible. Traveling is one of the ways I have enjoyment in mine. If this vacation goes well our next vacation will be an Alaskan Cruise!

Do you have any "Tips and Tricks" to share with us?

Do you have any children and youth resources that you think would be helpful for other families? Send them to us! Email info@alsab.ca

Welcome to our new Staff Members!

In November, Carla Falk joined the ALS Society of Alberta as a new member of our Client Services team covering the Red Deer area. Carla has been working as an OT for 19 years since graduating from the University of Alberta. Carla works part-time as an OT for Alberta Health Services in homecare where she also specializes in assessment and treatment of arthritis. Carla is also clinical lecturer for the University of Alberta.

In January, Monica Hudjj joined the ALS Society of Alberta as the temporary Equipment Program Coordinator while Jeremy Wojtkiw is off for 6 months enjoying time with his family and new baby boy. Monica's last job was at the Alberta Children's Hospital, assisting families with resources, funding, supports, and information. Prior to then she worked as an OT/PT assistant. Monica has a degree in Community Rehabilitation and Disability Studies from the University of Calgary.

Please join us in welcoming Carla and Monica to the ALS Society of Alberta!

Equipment

The ALS Society of Alberta is currently in transition from our Edmonton Equipment Vendor. We apologize if you have experienced any difficulties with obtaining equipment at this time. If you are having any issues, please contact Monica at the Provincial Office, or by email at Monica@alsab.ca

Caregivers Tax Credit

Federal Finance Minister, the Honourable Jim Flaherty recently announced the new federal Family Caregiver Tax Credit. The credit, which came into effect on January 1st, 2012, allows family caregivers taking care of an ill family member to claim an enhanced amount for a dependant under one of the existing dependency-related tax credits. This 15 per-cent non-refundable tax credit on an amount of \$2,000 will provide tax relief for caregivers including, spouses, common-law partners and minor children. The new tax credit could translate into as much as \$300 per family for 2012. Canadians will be able to claim the credit on their tax returns for 2012 and beyond.

In addition to the Family Caregiver Tax Credit, the federal government has also removed the \$10,000 limit on the amount of eligible expenses a taxpayer can claim under the Medical Tax Credit regarding a financially dependent relative.

For more information on these new initiatives, visit:

Family Caregivers Tax Credit - www.cra-arc.gc.ca/gncy/bdgt/2011/qa02-eng.html

Medical Expenses Tax Credit - www.cra-arc.gc.ca/gncy/bdgt/2011/qa07a-eng.html

Annual General Meeting

The ALS Society of Alberta will be hosting our Annual General Meeting on Saturday May 26th 2012. More information will be available at a later date.

Condolences

Our sincerest condolences go out to the families and friends who have lost a loved one. Thank you to those who kindly sent donations to the ALS Society of Alberta in memory of friends and loved ones affected by ALS. Your thoughtfulness is greatly appreciated.

Upcoming Support Groups and Information Sessions

All Support Groups and Information Sessions are provided free of charge. They are offered in casual group settings that provides everyone with an opportunity to share their experiences, information and support.

Calgary - ALS Support Group

This group provides support to people living with ALS, their spouses, significant others, friends and families.

Dates: March 31, April 28, May 26

Time: 1:30 pm - 3:30 pm

Location: Rotary Challenger Park, Canada Alberta Century

Field House (3688 48Avenue NE)

For more information, contact Jane at 403-714-8211 or email lane@alsab.ca.

Calgary - ALS Family and Spousal Group

This warm and casual group is for people who are living with someone affected by ALS.

Dates: Once a Month Time: 6:30 pm - 8:30 pm

For more information, contact Megan at 403-921-7101 or email Megan@alsab.ca.

Calgary - PLS Support Group

This group if for people living with PLS; friends, family and significant others are welcome too!

Dates: Every Second Month
Time: I pm - 3 pm

Location: 1718 14th Avenue NW

For more information, or if you are interested in attending, please call Megan at 403-921-7101 or email Megan@alsab.ca.

Edmonton - ALS Support Group

This group is for those living with ALS, families, partners, and caregivers.

Dates: Third Tuesdays of the Month

Time: 1:30 pm - 3:00 pm

Location: ALS Society of Alberta, Edmonton Office

Please call 780-487-0754 to register.

Edmonton - Life After Loss Support Group

Supporting someone living with ALS is intense and challenging. Survivors naturally may feel an additional sense of loss related to the caregiving role after the death. How do we adapt to this new life? How do we reconnect with friends, family and a job. after giving all our time and attention to our loved one? Focus of our discussions will be on the changes after the loss of a loved one.

Date: Thursday, March 15 Time: 1:30 pm - 3:30 pm

Location: ALS Society of Alberta Edmonton Office

Please call 780-487-0754 to register.

Leduc - ALS Support Group

Dates: Third Saturdays of the Month

Time: 1:30 pm - 3:30 pm

Location: Karunia House (4701 – 49 Avenue, Leduc)

Please call 780-487-0754 to register.

Lethbridge - ALS Support Group

For more information, contact Janice Zoeteman at 403-393-2663 or by email at janice@alsab.ca.

Red Deer - ALS Support Group

This is a group for people living with ALS and also welcomes friends, family members, and significant others.

When: Every Second Month

For more information, contact Jane at 403-714-8211 or email Jane@alsab.ca.

Red Deer - ALS Family/Spousal Group

The Red Deer group is for those who have lived or are currently living with a spouse or family member with ALS.

When: Third Thursdays of the Month

Time: I pm - 3 pm

The group is co-facilitated by Esme Tyson and Jane Rivest. Please call Jane at 403-714-8211 or email Jane@alsab.ca for more information and location details.

Support for Champions

The ALS Society of Alberta's Support for Champions program is dedicated to providing financial assistance to children and youth (aged 18 and under) who have been affected by ALS. The program provides the opportunity for children and youth to pursue extracurricular activities. The program is not means-tested and is confidential. Some examples of activities applied for by previous participants are: piano lessons, basketball lessons, and camp.

If you would like to apply for funding from the Support For Champions program, please contact Stephanie at 403-228-3857 or by email at Stephanie@alsab.ca. If you would like to donate to this program, please contact the Provincial Office.

WALK for ALS

The WALK for ALS is a fun, family friendly event that occurs across the country each year in more than 84 communities and is organized by local volunteers. In 2011 the WALK for ALS generated over \$3 million, thanks to more than 19,000 walkers and more than 165,000 donors.

All participants are encouraged to solicit donations. To make fundraising easy, each participant that registers on-line is able to set up a personal web-page with access to online fund raising tools.

For more information, visit www.WalkForALS.ca or call the ALS Society of Alberta's Provincial Office.

2012 WALK for ALS Locations in Alberta

Camrose Date: Saturday June 23

Location: Mirror Lake (Bill Fowler

Centre)

Coordinator: Brandee Fossen

Phone: 780-686-0598

Email: CamroseWalk@alsab.ca

Fort McMurray

Date: August Location:

Coordinator: Brad Gaulton

Phone: ALS Society of Alberta Provincial

Email: FortMcmurrayWalk@alsab.ca

Red Deer

Date: Saturday June 23

Location: Great Chief Park @ Bower

Ponds

Coordinator: Michelle Parker/Deb Hansen Coordinator: Yvonne Cadwell

Phone: ALS Society of Alberta Provincial

Email: RedDeerWalk@alsab.ca

Cold Lake

Date: lune Location: Lutheran Church at

Millenium Trail

Coordinator: Michelle Feduniak

Phone: 780-639-2360

Email: ColdLakeWalk@alsab.ca

Lethbridge

Date: Saturday September 8 Location: Henderson Lake Park Coordinator: Susie Bettger

Phone: 403-308-3739

Email: LethbridgeWalk@alsab.ca

Spruce Grove

Date: Saturday June 2

Location: Central Park (450 King

Street)

Phone: 780-960-3088

Email: SpruceGroveWalk@alsab.ca Email: VegrevilleWalk@alsab.ca

Edmonton

Date: Saturday June 9 Location: Hawerlak Park Coordinator: Lindsay Cashin

Phone: ALS Society of Alberta Edmonton

Email: EdmontonWalk@alsab.ca

Okotoks

Date: Saturday June 30 Location: Cimarron Park Coordinator: Paige Boychuk

Phone: ALS Society of Alberta Provincial

Email: OkotoksWalk@alsab.ca

Vegreville

Date: Saturday August 18 Location: Elks Kinsmen Park

Coordinator: Dina Coers/Kayla Brennick Phone: ALS Society of Alberta Provincial

Office

If you would like to volunteer for a WALK for ALS, or host a WALK for ALS in your community, please contact Lindsay at 403-228-3857 or email Lindsay@alsab.ca.

Betty's Run for ALS

Inspiring Care, Hope and Community

Since 1997 Betty's Run for ALS has raised over \$4.5 million for ALS research, equipment and client support. A very special thank you goes to all for the incredible support over the years. We welcome all ALS families and friends to the 16th Annual Betty's Run for ALS.

Date: Sunday June 10 9 am Start Time:

North Glenmore Park, Calgary Place:

For more information, visit www.bettysrun.ca or email bettyrun@alsab.ca

Charitee Golf Tournament for ALS

Join us for the 10th Annual Charitee Golf Tournament for ALS. Funds raised help support the ALS Society of Alberta, and the University of Calgary ALS Clinic.

Date: Monday June 18

Time: 12:00 pm - 1:15 pm - Registration and Lunch

Pinebrook Golf & Country Club Location:

For more information on the tournament, becoming a sponsor or registering a team, contact Lindsay at 403-228-3857 or email Lindsay@alsab.ca.

Upcoming Third Party Events

An Evening of Vehicles and Violins Gala 2012

The Calgary Motor Dealers Association is pleased to invite you to the 2012 Vehicles and Violins Gala. Enjoy delectable international cuisine, entertainment as arranged by musicians of the Calgary Philharmonic Orchestra, live and silent auctions, and an exclusive preview of the 2012 Calgary International Auto and Truck Show. The ALS Society of Alberta is one of the honoured recipients of the Vehicles and Violins Gala.



Date: Tuesday March 13 Time: 5:30 pm - 10:00 pm

Location: BMO Centre, Stampede Park, Calgary

Tickets are \$150 + gst. If you would like to be invited to this exclusive event, please go to www.autoshowcalgary.com and sign up to become an invited guest and purchase a ticket! You can also call 403-974-0707 or email cmda@telus.net.

Reach Out and Touch, Featuring Deanna Dubbin and Friends

The evening will feature a musical review of local singer Deanna Dubbin, as well as a silent auction.

Date: Saturday March 24

Time: 7 pm - 8 pm - Cocktails/Auction

8:15 pm - 10:00 pm - Show time

Location: The Lantern Community Church (1410 10 Ave SE, Calgary)

Tickets are \$35. To purchase a ticket, or to donate by cash or cheque call Nina Dubbin at 403-274-3704, or email ninamaedubbin@yahoo.ca. To purchase tickets or to donate by credit card, call the ALS Society of Alberta Provincial Office or email Lindsay@alsab.ca.

14th Annual ALS Charity Dinner

Colleen Christie will be hosting her 14th Annual ALS Charity Dinner in Lloyminster, Alberta on April 28th. The evening will have a silent auction, dinner and Herb Dixon, Canadian Master Sound Impressionist and Comedian.

Date: Saturday April 28

Time: 5:30 pm – Cocktails/Dinner Location: Lloydminster Stockade

Tables for 8 are \$400 or \$55/ticket. For more information, contact Linda Allen at 780-875-8513.

Seven8ty Season Opener

Annual season opener car meet for the local automotive enthusiast community. There will be a BBQ, Silent Auction and a Show'n Shine for the ALS Society to help ring in the new season! Funds will support both the ALS Society of Alberta and the ALS Society of Canada.

Date: Saturday May 5

Location: United Cycle Parking Lot (7620 Gateway Blvd NW, Edmonton)

For more information, contact Marie Lefreniere at 780-994-2284 or mlafreni@hotmail.com

Ist Annual Golf Tournament

This fundraiser is organized in support of Derek Sasynuik who is living with ALS. All funds raised will support the ALS Society of Alberta. Entry fee is \$225 or \$800 for a team which includes a hot breakfast and a steak dinner. There will be prizes throughout the day and a live and silent auction during dinner.

Date: Friday August 17

Location: Coloniate Golf and Country Club (10 Country Club Drive, Beaumont)

For more information, contact Tanya Sasynuik at 780-868-8871 or by email at tanyasas@hotmail.com

If you would like to host a Third Party Fundraiser for the ALS Society of Alberta, please contact Lindsay at 403-228-3857 or email Lindsay@alsab.ca.

Third Party Fundraisers September 2011 - January 2012

A big thank you goes out to everyone who has taken the time to raise awareness and funds for the ALS Society of Alberta.

Here are a few of the wonderful fundraisers put on in support of the society in last couple of months:

Poker Fun

On September 23rd and 24th, the Red Deer Optimist Club hosted a fun Poker Tournament to raise funds for their club, along with the ALS Society of Alberta. Over \$2,700 was raised for ALS! Thanks so much for your support! (Photo A)

Songs from the Heart

Carol Whaley hosted the Songs from the Heart fundraiser on September 25th at the Fifth Avenue Memorial United Church in Medicine Hat. The event raised over \$300, thanks so much Carol! (Photo B)

Judy Schweitzer ALS Curl for a Cure

Carrie Mello organized her 2nd Annual Judy Schweitzer ALS Curl for a Cure on November 12th at the Michener Hill Curling Club in Red Deer. The second annual event raised over \$4,700! Thank you Carrie for your hard work!

Do you have any ideas for upcoming fundraisers? Contact Lindsay at 403-228-3857 x108 or email Lindsay@alsab.ca to share your ideas and get started.





Dueling Pianos

On December 1st, Tony Gize organized the *Dueling Pianos* event, which featured two dueling pianos live from The New York, New York Hotel in Las Vegas. The event was held at the Over Time Lounge in the Rob Ebbesen Arena in Airdrie. Over \$4,800 was raised for the ALS Society of Alberta. Thank you Tony for organizing this great event! (Photo C)

A Christmas Carol Project

On December 8th, the Pumphouse Theatre in Calgary invited the ALS Society to host an information and donation table at their performance of *A Christmas Carol Project*. The evening raised over \$600 for the ALS Society of Alberta. Thank you to the Pumphouse Theatre Staff for inviting us back again this year!

Darby Chrest Memorial Bowling Event

On January 1st 2012, the 3rd Annual Darby Chrest Memorial Bowling Event was held at Heritage Lanes in Red Deer by Shelby Chrest. This fun event had over 34 teams registered and was a great way to celebrate the New Year. Over \$7,500 was raised! Thanks so much Shelby for organizing this annual event! (Photo D)





D

Donation Form

I would like to join the ALS Society of Alberta's Monthly Giving Program

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	iety of Alberta to charge my moi ard information below)	nthly donation of \$	to my cred card at the	e beginning / middle (circle)) of each
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Phone	Email				
Credit Card Informa	ation				
Select: Visa	MasterCard	American Expre	ss		

Please return form to the ALS Society of Alberta Provincial Office.

Your gift will help us to make everyday the best possible day for those living with and affected by ALS.

Privacy Statement: Your personal information will not be abused, sold or shared without your knowledge or consent. For more information, please call the ALS Society of Alberta's Provincial Office.

Tax Reciepts will automatically be issued for donations of \$20 or more.