



The ALS Society of Alberta

Prairie to Peak



Exciting Announcement!

We are very excited to announce that we have launched our new ALS Society of Alberta website!

Visit us at www.alsab.ca and let us know what you think!

Calgary Motor Dealers Association - Vehicles and Violins Gala



CMDA Executives (L-R): Ben Maitland, Jim Gillespie, and Andrew Robinson.

Missing: Darin Schotanus

Thank you to Mr. Jim Gillespie and the Calgary Motor Dealers Association for choosing the ALS Society of Alberta as one of the recipients of this year's annual Vehicles and Violins Gala. This Gala is one of the premier events in Calgary that raises much needed funds and awareness for charitable organizations.

It was a spectacular evening with international food, refreshments and music by the Calgary Philharmonic Orchestra. The Gala was a huge success and was supported by so many generous donors.

New this year was the wine tree raffle. With the volunteer efforts from the Scotiabank Western Dealer Finance Centre and Scotia Dealer Advantage senior staff, Warren Sandbeck, Greg Johnson, Al Cavanagh, Glenn MacLaren, Joe Oviatt and Darren Kiley, the two raffles sold out!

We could not do what we do without the support of community philanthropists like the Calgary Motor Dealers Association. THANK YOU!

ALS Society Events **UPCOMING**

Betty's Run for ALS

Betty's Run for ALS is one of the signature events for the ALS Society of Alberta. In the 16 years since its inception, Betty's Run has raised over \$5 million for ALS awareness, client services, equipment and research to find a cause and cure for this terrible disease. Join us for the 17th annual event!

Date: June 9

Time: 9:00 a.m.

Location: North Glenmore Park, Calgary

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

or call the hotline at 403-297-0569



WALK for ALS

The WALK for ALS is a national event and one of the signature events for the ALS Society of Alberta. In 2012 there were ten WALKs for ALS across the Province that raised over \$476,000! The WALK for ALS is organized by a hardworking group of volunteers and the ALS Society of Alberta.

Join us to walk this year in your community!

June

Cold Lake - June 1

Registration: 10:00 a.m. Start: 11:00 a.m.

Location: Lakeland Lutheran Church on Millennium Trail

Email: coldlakewalk@alsab.ca

Spruce Grove - June 1

Registration: 9:00 a.m. Start: 10:00 a.m.

Location: Central Park

Email: sprucegrovewalk@alsab.ca

Peace District - June 6

Registration: 5:30 p.m. Start: 6:00 p.m.

Location: River Front Park

Email: peacriverwalk@alsab.ca

Edmonton - June 8

Registration: 9:00 a.m. Start: 10:00 a.m.

Location: William Hawrelak Park

Email: edmontonwalk@alsab.ca

Camrose - June 22

Registration: 10:00 a.m. Start: 10:30 a.m.

Location: Mirror Lake Park (Bill Fowler Centre)

Email: camrosewalk@alsab.ca

Hinton - June 22

Registration: 10:30 a.m. Start: 11:00 a.m.

Location: Beaver Boardwalk at Maxwell Lake Picnic Tables

Email: hintonwalk@alsab.ca

Red Deer - June 22

Registration: 9:00 a.m. Start: 10:00 a.m.

Location: Great Chief Park

Email: reddeerwalk@alsab.ca



August

DeBolt - August 17 *NEW*

Registration: 8:30 a.m. Start: 9:30 a.m.

Location: DeBolt Centre (Mainstreet)

Email: deboltwalk@alsab.ca

Fort McMurray - August 18

Registration: 10:00 a.m. Start: 11:00 a.m.

Location: Birchwood Trails at Birchwood School Field
(190 Tamarack Way)

Email: fortmcmurraywalk@alsab.ca

Vegreville - August 24

Registration: 10:00 a.m. Start: 11:00 a.m.

Location: Elks Kinsmen Park

Email: vegrevillewalk@alsab.ca

September

Lethbridge - September 7

Registration: 8:00 a.m. Start: 9:00 a.m.

Breakfast: 10:00 a.m. - Noon

Pancakes, Bacon, Eggs, Coffee and Orange Juice

Location: Henderson Lake Park

Email: lethbridgewalk@alsab.ca

Volunteers are needed on WALK for ALS Committees across the province! If interested, please contact Lindsay at 1-888-309-1111 or email Lindsay@alsab.ca

ALS Society Events **UPCOMING**

2013 Annual General Meeting

The Amyotrophic Lateral Sclerosis (ALS) Society of Alberta Annual General Meeting will be held on May 25 at the ALS Society of Alberta #250, 4723 1 Street SW Calgary, Alberta at 12:00 p.m. Lunch will be served from 12:00 p.m. to 1:00 p.m. Please RSVP by May 17 to Diane@alsab.ca or by calling the ALS Society of Alberta Provincial Office at 1-888-309-1111. Seating is limited.

ALS Charitee Golf Tournament

Join us for the 11th Annual ALS Charitee Golf Tournament. Funds raised help support the ALS Society of Alberta and the University of Calgary Neuromuscular Clinic.

Date: June 17

Time: 12:00 p.m. – 1:15 p.m. – Registration and Lunch

Location: Pinebrook Golf & Country Club, Calgary

For more information or to register, visit www.ALSChariteeGolf.ca, call 1-888-309-1111 or email Lindsay@alsab.ca



Events **UPCOMING**

If you would like to host a fundraiser, please contact Lindsay at 1-888-309-1111 or by email at Lindsay@alsab.ca



The 9th Annual Volunteers In Action Open

The Co-operators Volunteers In Action Committee is committed to supporting organizations that focus on families and children and are proud to partner with The ALS Society of Alberta for the 2013 VIA Open.

Date: June 6

Location: Valley Ridge Golf Club

For more information please contact: David Christensen at 403-692-6051 or email david_christensen@cooperators.ca

ALS Quonset Days - The Greatest Outdoor Show on Dirt!

Live music including: Jay Bowcott & the BadHatters, The Chevelles, Rock n' Roll Dance Band, Phoenix and Adam Gregory! The event will also include a live and silent auction.

Date: July 19-21

Location: Seven Persons

For more information, visit <http://quonsetdays.webs.com>, call 403-504-9523 or 403-504-9537.

Saz's Soldiers 2nd Annual Charity Golf Tournament

Team registration is \$800 and also includes a hot breakfast, steak dinner as well as a live and silent auction.

Date: August 16

Location: Colonial Golf and Country Club, Beaumont

To register, contact Tanya Sasyniuk at 780-868-8871 or by email at tanyasas@hotmail.com. To donate online, visit www.alsab.ca

Community Support

Red Deer & District Community Foundation

Thank you so much to the Red Deer & District Community Foundation for funds to support our Equipment Loan Program. We are very appreciative of the \$2,650 that will help us to provide communication and mobility equipment for our clients.

Community Initiatives Program

Honourable Heather Klimchuk, Minister of Alberta Culture granted the ALS Society \$30,000 through the Community Initiatives Program for our Equipment Loan Program. Minister Jonathan Denis presented the cheque to Board Member Jan Desrosier. Thank you so much!



*Honourable Jonathan Denis
and Board Member Jan Desrosier*

City of Edmonton

Mayor Stephen Mandel of the City of Edmonton granted \$17,500 to the ALS Society in recognition of the benefits provided to the citizens of Edmonton through our programs and services. The funds came through the Community Investment Operating Grant and will go to support operating costs.

Edmonton Realtors Foundation

Thank you so much to the Edmonton Realtors Foundation who granted the ALS Society \$13,600 to purchase a Power Wheel Chair for our Equipment Loan Program. We have had such great support from the foundation over the past years and we are very appreciative.

ATB Financial

We are very thankful to ATB Financial who is a great supporter of the ALS Society. ATB donated \$2,000 for the upcoming ALS Quonset Days event that is in Seven Persons, July 19-21. ATB also supported the 2013 Vehicles and Violins Gala through sponsorship. Thank you so much for your continuous support!



*ATB Financial representative presenting cheque
to Tara Pentney, ALS Society vice chair.*

Updates

New ALS Study at the University of Calgary

Article submitted by: University of Calgary Neuromuscular Clinic

We have just begun to recruit patients for a new ALS study sponsored by Cytokinetics, here at the University of Calgary.

BENEFIT-ALS is designed to enroll approximately 400 patients who will first complete one week of treatment with open-label Tirasemtiv at 125 mg twice daily. Following completion of the open-label period, patients will be randomized to receive 12 weeks of double-blind treatment with twice-daily oral ascending doses of Tirasemtiv beginning at 125 mg twice daily and increasing weekly up to 250 mg twice daily or a dummy dose titration with placebo. Clinical assessments will take place monthly during the course of treatment; patients will also participate in follow-up evaluations one and four weeks after their final dose.

The primary efficacy analysis of BENEFIT-ALS will compare the mean change from baseline in the ALS Functional Rating Scale in its revised form (ALSFRS-R) on Tirasemtiv versus placebo. Secondary endpoints will include Maximum Voluntary Ventilation (MVV) and other measures of respiratory and skeletal muscle function. Patients taking riluzole at the time of enrollment and who are randomized to receive Tirasemtiv will receive riluzole at a reduced dose of 50 mg daily. Cytokinetics plans to conduct this trial at over 70 sites across the United States, Canada, and several European countries.

Upright vital capacity needs to be >60% and patients need to have diminished (but some) grip strength in at least one hand.

Interested patients can contact Janet Petrillo 403-210-7006 or email at japetril@ucalgary.ca for further details.

Third Party Events FUNDRAISERS

Darby Chrest Memorial Bowling

Thank you to Shelby Chrest and the group at Heritage Lanes in Red Deer who once again organized the Darby Chrest Memorial Bowling event. The fundraiser brought in over \$5,000! We are so thankful for your ongoing support.

Go Tire Dragon's Den Launch Party

On January 13, Go Tire in Red Deer supported the ALS Society at their Dragon's Den Launch Party. The event took place at Western Park and Grounds and over \$2,000 was donated through the toonie bar and raffle. Thank you so much to Go Tire, Heather Murphy and Branson Lepage for your support!

Coach Cranney ALS Charity Challenge



From December 2012 - February 10, 2013, the Bow River Bruins Bantam hockey team worked together to raise funds in honour of their hockey coach, Trevor Cranney who had been diagnosed with ALS. Funds were raised online, through raffle sales, as well as a silent auction and dinner at their hockey tournament in Banff.

Over \$37,000 was raised through this event!

Thank you so much to Todd Greiner and the organizing committee, parents of the Bow River Bruins team, and the Babes team for all you did to raise funds and awareness!

South Calgary Ringette Association Bake Sale



On March 2, the South Calgary Ringette Association held a Ringette game and bake sale at the Flames Community Arena. Players collected donations in honour of friend Karen Moro and raised over \$3,200! Thank you so much for organizing this fun event!

Averie's 2nd Birthday Party



On March 10, Julie Shipley-Strickland held a party for her daughter Averie's 2nd birthday. Instead of asking for gifts, guests brought donations for the ALS

Society. Over \$800 was raised in honour of Averie's Grandfather who lived with ALS. Thank you for your support!

Ron Church Fine Art and Design



From March 21 - 24, Ron Church set up a booth for his artwork at the Edmonton Home and Garden Show. Through his artwork, Ron will be donating 10% of each sale to the ALS Society. To view his art, please visit his website at www.ronchurch.ca

Heal Your Soul with Words and Music

On April 9, Manon Mitchell hosted a fundraising event at Cardel Theatre in Calgary. The fundraiser was a recital of guided imagery and live music by Manon and Serge Mazerand. The event was to honour Danny Haddad and raised over \$1,200! Thank you so much for your support!

Do you want us to feature your fundraiser in the Prairie to Peak newsletter?

Send in your information to Lindsay@alsab.ca or call 1-888-309-1111

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.

Power Outage Tips

Power outages can bring significant challenges if you are living with ALS and are using equipment that needs to be plugged in. In order to be prepared, we suggest you have the following (all with working batteries):

- nightlights - if the power goes out, the nightlight will come on letting you know right away that there is a power outage. If you have one without batteries, and the light goes off in the dark, you will also know the power has gone out.
- flashlights
- cell phone
- portable power pack (such as an Eliminator PowerBox 700w) - can be purchased at a hardware store to temporarily power equipment during the outage.

Get out into Nature



Push To Open Nature Society "is a network of groups and individuals that use their abilities to enrich lives through connection with nature, adaptive outdoor activities, and sharing stories of inclusion". This provincial non-profit organization strives to connect you with adaptable outdoor equipment and the supports that will make your outdoor goals possible. Visit: www.pushtoopen.ca, call 403-340-4869 or email bev.randers@gov.ab.ca.

Summer Getaway

The William Watson Lodge Society at Peter Lougheed Provincial Park offers accommodations where Albertans with disabilities can enjoy the outdoors at a reasonable cost. There are 22 accessible cottages, 6 camp sites, picnic sites and 18 km of accessible trails. There are units that come with ceiling tracks, lifts, roll-in showers and shower commodes. All you need to bring is your bedding, toiletries and food. Please note that you are required to book three to four months in advance. For more information, please call 403-591-7227 or visit www.williamwatsonlodgesociety.com.

Parking Placards for People with Disabilities



A person must be unable to walk 50 meters (150 feet) in order to qualify for a parking placard. Applications for the placard can be obtained from any Alberta Registry or on the Service Alberta website. The application form must be completed by a certified medical professional based on their assessment of your need for the parking placard. Once the form has been completed, you can take it to any Alberta Registry where a parking placard will be issued.

There are many resources available for children and youth who are affected by ALS. Here are a few books that you may find helpful!

Puppet Plays for Grieving Children By Sharon Rugg, LCSW (\$25)



Acting out different experiences of grief and loss through puppet plays offers a creative alternative for helping children. This book includes 16 different puppet plays covering a wide variety of losses, discussion questions for each play, and instructions for making stages and puppets.

To order this book and other resources, visit www.risingsuncenter.com/puppet_plays.htm

Weird Is Normal When Teenagers Grieve By Jenny Lee Wheeler (\$5-9)



Are You a Teenager Dealing with Grief? You've got to pick up this book. It was written by a grieving teen for grieving teens. Like you, author Jenny Lee Wheeler has experienced (and is still experiencing) the challenges of how to grieve in an adult world filled with "shoulds" and unrealistic expectations.

To order a copy, please visit www.weirdisnormal.org and click on "Buy from Amazon".

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.

ALS Support Groups

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 & Spousal Support Group

These warm and casual groups are for people who have lived with, or are currently living with someone affected by ALS.

Calgary

ALS Support Group

Dates: May 4
May 25
July 27

Time: 1:30 p.m. – 3:30 p.m.

Place: Rotary Challenger Park
Canada Alberta Century
Field House
3688 48 Avenue NE

ALS Family & Spousal Support Group

Dates: May 16
June 13
July 11

Time: 6:30 p.m. – 8:30 p.m.

Place: 8211 Churchill Drive SW

Contact Jane at 403-714-8211 or email Jane@alsab.ca for more information on Calgary's ALS support groups.

PLS Support Group

This group is for people living with and affected by PLS.

Dates: Monthly

Exact dates to be finalized

Time: 1:00 p.m. – 3:00 p.m.

Place: 1718 14 Avenue NW
Renaissance Condo Complex
at North Hill Mall

Contact Megan at 403-620-1358 or email Megan@alsab.ca if you are interested in attending or for more details.

Calgary

Staying in Touch (NEW!)

This group was created for those who have lost someone to ALS. This casual group gets together to reconnect with familiar faces, chat with others who have been through a similar journey and share some support and happy memories.

Dates: Every two months

Exact dates to be finalized

Time: 6:30 p.m. - 8:30 p.m.

Place: ALS Society Provincial Office

Contact Megan at 403-620-1358 or email Megan@alsab.ca if you are interested in attending or for more details.

Edmonton

ALS Support Group

Light refreshments will be available.

Dates: Every third Tuesday of the month
May 21
June 18

Time: 1:30 p.m. – 3:00 p.m.

Place: ALS Society Edmonton Office
#314 Circle Square, 11808
St. Albert Trail NW

Life After Loss Support Group

The focus of our discussions will be on the changes after the loss of a loved one.

Dates: Every third Thursday of the month

May 16

June 20

Time: 1:30 p.m. – 3:30 p.m.

Place: ALS Society Edmonton Office
#314 Circle Square, 11808
St. Albert Trail NW

Contact 780-487-0754 for more information or to register for Edmonton's support groups.

Leduc

ALS Support Group

Dates: Every third Tuesday of the month

May 21

June 18

Time: 1:30 p.m. – 3:30 p.m.

Place: Karunia House
4701 49 Avenue

Contact 780-487-0754 for more information or to register for Leduc's support group.

Lethbridge

ALS Support Group

Dates: Every last Friday of the month

Time: 2:00 p.m.

Place: North Bridge Seniors Centre
1904 13 Avenue N

Contact Janice at 403-393-2663 or email Janice@alsab.ca for more information.

Red Deer

ALS Support Group

Dates: Every other month

June 2

Time: 1:00 p.m. – 3:00 p.m.

Place: MS Society Office
#105 4807 50 Avenue

ALS Family & Spousal Support Group

This group is co-facilitated by Esme Tyson and Carla Falk.

Dates: Every third Thursday of the month

May 16

Time: 1:00 p.m. – 3:00 p.m.

Place: Contact for details

Contact Carla at 403-357-4791 or email Carla@alsab.ca for more information on Red Deer's support groups.



The ALS Society of Alberta



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

PROVINCIAL OFFICE

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EDMONTON OFFICE

#314 Circle Square, 11808 St. Albert Trail NW | Edmonton, AB T5L 4G4
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Fax: (780) 486-3604 | Email: societynorth@alsab.ca

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Donation Form

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

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)*

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 _____ Authorizing 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:

Surname _____ First Name _____

Address _____

City/Town _____ Province _____ Postal Code _____

Phone _____ Email _____

Credit Card Information

Select: Visa _____ MasterCard _____ American Express _____
Credit Card Number _____ Expiry Date _____

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

Your gift will help us to make each day 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.

Charitable Tax Receipts will automatically be issued for donations of \$25 or more.