



## 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 Provincial Office

# 250, 4723 1st Street SW  
Calgary, Alberta T2G 4Y8

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Fax: (403) 228-7752  
Toll Free: 1 (888) 309-1111  
Email: info@alsab.ca

### Edmonton Office:

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11808 St. Albert Trail NW  
Edmonton, AB T5L 4G4

Phone: (780) 487-0754  
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Toll Free: 1 (866) 447-0754

### Board of Directors

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Cathy Martin

#### Vice Chair

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## Message from the ALS Society Board of Directors

Welcome to the first edition of our Newsletter in 2011 – the year that marks our 25th Anniversary as a Society. We have come a long way in 25 years, and yet we are still a young society - one that is in a great position to continue to make a positive difference.

The Board of Directors has always been dedicated to fulfilling our vision of ensuring that each day is the best possible day for people living with, and affected by ALS. We do this through the leadership provided by our ten board members who govern the work of the society through our involvement on various committees and initiatives. Three years ago, we developed our Five Year Strategic Plan, and we based our committee structure around the Pillars of Governance, Finance, Human Resources and Advocacy.

The board members have been busy ensuring that our policies are in place, and that they reflect the highest standards in the non-profit sector. We are pleased to work with our partners and other stakeholders to bring issues to government decision makers in order to increase the accessibility of supports and services needed by people living with ALS.

There are many rewards for being a member of the Board of Directors for the ALS Society of Alberta. The most enjoyable occasions are when we get to meet you, the members of our society at the many events in which we have the privilege to participate. You are the soul of our organization and continue to motivate and inspire us to do our best.

We look forward to the many good things to come in this, our silver anniversary year.

Cathy Martin  
Chair

## We Moved!

The ALS Society of Alberta's Provincial office moved at the end of December.

Our new address is:

Suite 250, 4723 1st Street SW  
Calgary, AB T2G 4Y8

We would like to thank everyone who helped out for our move by providing pro bono work to the ALS Society. Some of the people we'd like to recognize are: Dwayne, Dome Properties, Irwin, and Saskatchewan Minerals Inc.

## Canadian Neuromuscular Disease Registry

The Canadian Neuromuscular Disease Registry (CNDR) is a Canada-wide registry of people diagnosed with neuromuscular diseases. The registry collects important medical information from people across the country to improve the understanding of neuromuscular disease and accelerate the development of new therapies. Joining the registry is voluntary, confidential, and free. Participants may withdraw from the registry at any time, and do not receive money for participating in the CNDR. No procedures or treatments are required to be part of the CNDR, and no extra visits to the doctor are required.

Gathering information from people in Canada diagnosed with neuromuscular diseases could help researchers see patterns and make new observations to help them unlock the secrets of how these diseases work. This knowledge can be used in many ways, including:

- to help understand the burden these diseases create and direct resources to where they are needed most
- to increase understanding of diseases
- to enable new research studies and clinical trials
- to improve clinical care and disease management
- to improve the chances of finding a cure.

The registry is a national research project being led here in Alberta by Dr. Korngut at the University of Calgary, Faculty of Medicine. If you are interested in registering, or for more information, visit [www.cndr.org](http://www.cndr.org) or call 1-877-401-4494.



### Hill Day

On October 15th, 2010, Federal Minister Jean-Pierre Blackburn announced that Veterans with ALS are now able to receive disability benefits, treatments and home care support – services that are greatly needed by veterans and their families who are affected by this devastating disease. In the past, some Veterans were dying before they had a chance to submit their case to Veteran Affairs Canada. The announcement followed months of advocacy initiated by ALS Canada. This photo was taken following the announcement.

### Top Chef – ALS Style!

On November 1st 2010, the Edmonton ALS Office hosted an evening of Top Chef ALS Style. At the workshop, clients and caregivers learned how to modify and present food that is nutritious, appealing to the eye, pleasant tasting and the correct consistency to match the client's swallowing needs. The lesson was presented by Shameem Kizar and Kerry Adams of the ALS Clinic in Edmonton.



### New Honourary Patron of the ALS Society of Alberta

The ALS Society of Alberta is proud to announce His Honour Colonel (Retired) the Honourable Donald Stewart Ethell, OC, OMM, AOE, MSC, CD, Lieutenant-Governor as our new Honourary Patron for the ALS Society of Alberta. We are very excited to have His Honour as our new Honourary Patron and we would like to take this chance to welcome him to the ALS Society Family.

### 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.

## Great Kids Award!



On October 16th, 2010, Emily Richardson from Sherwood Park was honoured as a “Great Kid” for her positive contribution to her family, school and community. After watching her grandmother deteriorate and then pass away from ALS, Emily became an avid and vocal supporter of the ALS Society of Alberta. She participates in Alberta Walks for ALS every year, raises money and awareness for the cause and has handcrafted fairies out of silk flower petals to sell as a fundraising initiative.

Albertans nominated over 160 children and youth from across the province for the award, and Emily was chosen as one of 16 winners. As a Great Kid Award winner, Emily received a trophy and a prize package that included an evening at the Fantasyland Hotel with her family, a laptop computer from IBM and attractions passes from West Edmonton Mall. Emily was presented her award by Premier Stelmach and the Minister of Children and Youth Services, Yvonne Fritz.

Thank you so much Emily for all of your hard work and support - and congratulations!!

## Support for Champions

On November 30, 2010, the ALS Society of Alberta lost one of our key volunteers that dedicated her time to the families of people living with ALS. Cindy Rivest, the daughter of Jane and Bob, passed away suddenly in hospital. Cindy gave of her time and energy alongside her Mom to volunteer at ALS events, help with administrative needs of the Society and volunteered in the children’s area year after year at Betty’s Run. Cindy was dedicated to families affected by ALS.

In memory of Cindy, her family asked that donations be directed to our *Support for Champions* Program. On behalf of the ALS Society and all of the children that will benefit from the program, we would like to thank the Rivest family for their kind gesture, and thank you to all who generously donated funds to our Children’s Program. Cindy’s dedication and support will be remembered by all of us and by all of the children she will touch through this year’s *Support for Champions* Program.

## Welcome to the newest member of our team!

Lindsay Schalin recently joined the ALS Society of Alberta as the Manager of Resource Development and Communications.

Lindsay holds a Arts and Science Certificate, and a Bachelor of Applied Communications Degree in Public Relations from Mount Royal University.

Lindsay’s previous experience includes working with Alberta Health and Wellness as a Junior Public Affairs Officer, an Assistant Campaign Coordinator with the Salvation Army; and most recently the Manager of Community Fundraising and Corporate Development with Kids Help Phone. Welcome to the ALS Society Lindsay!

## Volunteer and Staff Appreciation 2010

*Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.*

*~ Margaret Mead ~*

In November 2010, we recognized our staff and volunteers across Alberta who continue to devote their time to our cause. We started this annual event three years ago to celebrate and thank these generous individuals. Events were held in both Calgary and Edmonton and were well attended.

This year, we recognized many volunteers and staff for their dedication to the ALS Society of Alberta for five, eight, and 10+ years of service. Thank you to all of our volunteers, you are all part of the ALS family and help us to provide hope and care to people living with ALS.

## Upcoming Support Groups and Information Sessions

### ALS Support Groups - Calgary

This group is for people living with ALS, their spouses, significant others, friends and families. The group is very casual, supportive, and gives everyone an opportunity to share their experiences and learn from each other about what works for them.

Dates: April 2, May 14, June 4

Time: 1:30 p.m. - 3:30 p.m.

Location: Rotary Challenger Park (3688 – 48 Avenue NE) The building is called Canada Alberta Century Field House. It is the third building in around the circular roadway.

\* May 14th group will be held at Fort Calgary, more information to follow.

For more information, contact Jane at 403-714-8211 or email [Jane@alsab.ca](mailto:Jane@alsab.ca).

### PLS Support Groups - Calgary

If you or someone you know is living with PLS, please join us. We meet every second month to share information, resources and support one another. If you would like more information, please call Megan at 403-921-7101 or email [Megan@alsab.ca](mailto:Megan@alsab.ca).

### ALS Spousal Group - Calgary

This is a group which has been created to provide support specifically for the partners of people living with ALS. We meet once a month. If you are interested in meeting and sharing your experiences with others who are also affected by ALS, please call Megan at 403-921-7101 or email [Megan@alsab.ca](mailto:Megan@alsab.ca).

### ALS Support Groups - Red Deer

For information, contact Jane at 403-714-8211 or email [Jane@alsab.ca](mailto:Jane@alsab.ca).

### ALS Red Deer Family/Spousal Group

This group has met a few times in Red Deer, and is for people to provide and receive support from each other – all are people who lived or are living with their spouse or family member with ALS. Everyone who has attended in the past has mentioned how helpful it is to them. This group meets once a month. The co-facilitators are Esme Tyson and Jane Rivest. Please call Jane at 403 714 8211 or email [Jane@alsab.ca](mailto:Jane@alsab.ca) for more information.

### Edmonton Family Support Network

Dates: Third Tuesdays of the month

\*Please call ahead to register at 780-487-0754\*

Time: 1:30 p.m. to 3 p.m.

Location: ALS Edmonton Office  
#314, Circle Square,  
11808 St Albert Trail NW

Join our Family Support Network group to meet others, share issues and solutions, have fun and socialize. Light refreshments are provided. ALL WELCOME those with ALS, spouses, caregivers, and friends.

Facilitator: Susan Patenaude

## Government Benefits – Some Things You Should Know

Article Submitted by Melinda Hatfield

Organizations have recently come to the attention of Alberta Health Services that claim to aid individuals with medical conditions to ensure they get all tax credits, refunds and deductions to which they are entitled. Individuals have been successful with these type of organizations and have received refunds from the federal government that they did not know they were entitled to. Here is the catch: these for-profit businesses charge a hefty commission fee of 30% of your tax return!

### Here are some tips to help you and your family:

- \* Ensure you are dealing with a Government Agency.
- \* If you are unsure of what you are entitled to - ask your doctor, nurse, social worker “Would I be entitled to any financial assistance through the federal government as a result of my illness/disability?” to get the process started.
- \* Some of the benefits that you may qualify for include Canada Pension Disability, the Disability Tax Credit, and Compassionate Care benefits. Some benefits may go directly to you, others to your children or spouse.
- \*The Registered Disability Savings Plan (RDSP), the Canada Disability Savings Grant and the Canada Disability Savings Bond are three ways that the government is helping people with disabilities, and their families save for their future.

For more details on eligibility and how these programs work, please visit the Canada Revenue Agency website at: [www.cra-arc.gc.ca](http://www.cra-arc.gc.ca) and under the search option enter “Registered Disability Savings Plan.”

## Thank you !

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 the last couple months:

### Owen Blake

In September 2010, Owen Blake from Stettler, Alberta, launched a campaign to raise funds to find a cure for ALS. Owen, with the help of his friends and family, manually distributed 5,000 envelopes to people in the Stettler community to invite them to donate to ALS research and client services support. In two short months, Owen raised more than \$25,000. "I can't tell people how to avoid or prevent this disease because there is no known cure," Blake said, "but what I can and want to do is raise funds for research."

Owen Blake was a dedicated community volunteer. Even after his diagnosis of ALS, instead of choosing seclusion, Owen lived his vision to help find a cure. Unfortunately, Owen passed away on November 13, 2010.



### Realtors Community Foundation

The Realtors Community Foundation serving Edmonton and area was very generous in making a recent donation to the ALS Society of Alberta. Funds donated by the foundation went to purchase a Carroll Hospital Bed and Mattress, and a BHM Easytrack Freestanding System. Thank you so much!

### Darby Chrest New Years Day Charity Memorial Tournament

On January 1st, 2011 the second annual bowling tournament was held in honour of Darby Chrest in Red Deer. Darby was dedicated and passionate about bowling, and spent a lot of time at Heritage Lanes Bowling Alley. The event raised over \$4,300 – thank you to everyone who participated!

### Rosebud Run Sleddog Classic

On January 29th and 30th, the annual Rosebud Run Sleddog Classic took place in Didsbury. The Rosebud Run partners with the ALS Society for their event, as two of their founding members are currently afflicted with ALS. Rosebud Run Sleddog Classic is a nostalgic glimpse of the hardy men and women who met the challenge of winter travel in the snowbound north. Thank you so much for inviting us again to this great event.

### Hike 4 ALS

Amanda Mckeown organized the Hike 4 ALS at Canmore Nordic Centre, Banff Trail Hike on October 2nd 2010. Amanda lost her dad eight years ago to ALS and put on the event to show support for the disease. A lot of hard work and detail went into organizing this event, and the hike raised over \$3,050. Great work!!!

### The Christmas Carol Project

The ALS Society was invited to set up an awareness table at the December 11, 2010 viewing of "The Christmas Carol Project" put on by the Pumphouse Theatre in Calgary. The same group of musicians have performed the play for over 10 years and recently, two members of the Pumphouse family have been affected by ALS. The night's festivities brought in over \$600 in donations. Thank you so much to everyone who was there.

### Judy Schweitzer ALS Curl for a Cure Funspiel

Carrie Mello organized the Judy Schweitzer ALS Curl for a Cure Funspiel on January 15th in Red Deer at the Michener Hill Curling Club. The event was in honour of her mom, Judy who has ALS. The funspiel was a great success and brought in over \$3,500 - thank you so much!

### ALS Snow Hut

On February 9th and 10th, Kevin Mikulak from the University of Lethbridge worked along side his club for psychology and neuroscience students to build a snowcave to raise awareness and funds for ALS. Articles were all over the news about Kevin's snow hut, and the group raised over \$400 for the ALS Society of Alberta. Way to go guys!



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

## Upcoming ALS Society of Alberta Events

The **Walk for ALS** is coming up in several communities this year – here is a list of where you can attend. For more details visit our website at [www.WalkForALS.ca](http://www.WalkForALS.ca).

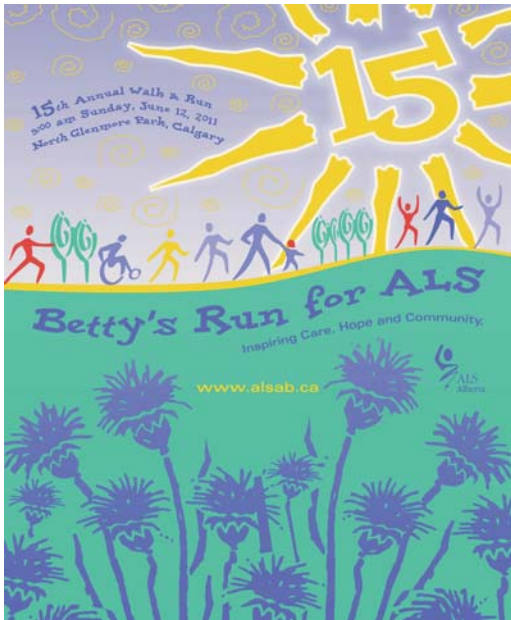
- \* Camrose - June 18, 2011
- \* Edmonton - June 11, 2011
- \* Grande Prairie - June 4, 2011
- \* Red Deer - June 18, 2011
- \* Cold Lake - June 18, 2011
- \* Fort McMurray
- \* Lethbridge - September 10, 2011
- \* Spruce Grove - June 4, 2011



If you are interested in hosting a Walk for ALS in your community, please contact Lindsay by phone at 403-228-3857 x108 or by email at [Lindsay@alsab.ca](mailto:Lindsay@alsab.ca).

The ALS Society of Alberta is celebrating our **25 Anniversary** this year! We will be combining the celebration with our **Annual General Meeting**. The event will be held on May 14, 2011 from 11 a.m. until 1 p.m. at Fort Calgary.

Please RSVP by May 7, 2011 to Marie Nicholson by phone at 403-228-3857 or by email at [Marie@alsab.ca](mailto:Marie@alsab.ca) if you would like to attend.



**Betty's Run for ALS** is celebrating its 15th Anniversary this year! The run/walk will take place on Sunday June 12th at North Glenmore Park in Calgary.

The Betty's Run Organizing Committee is inviting all families and friends from the past 15 years to join us for this exciting milestone! If you have any photos from the last 15 years you would like to share, please send them to [Lindsay@alsab.ca](mailto:Lindsay@alsab.ca).

For more event information visit [www.bettysrun.ca](http://www.bettysrun.ca) or call 403-297-0569.

Do you have HBC Rewards Points that you aren't using? Donate them to the ALS Society of Alberta! Its easy to do, here are the steps:

1. Visit [www.hbc.com/community](http://www.hbc.com/community)
2. Click on "Donate to an Existing Community"
3. Search for our group by entering our Public ID # 9927657
4. Select the percentage of points you would like to donate

You can earn HBC Rewards Points by shopping at The Bay, Zellers or Home Outfitters.

### Upcoming Third Party Events:

- \* Moustache March - April 2 - The Unicorn, Calgary
- \* ALS Curenament - May 15 - Duffield
- \* Gasoline Alley Harley-Davidson Poker Run - June 4 - Red Deer
- \* Rocky Mountain Rodeo - June 10 - 12 - Rocky Mountain House
- \* Casino - July 6, 7 - Calgary
- \* Poker Tournament - Sept 23-24 - Red Deer

Visit [www.alsab.ca/events](http://www.alsab.ca/events) for more information.



Photo Credit

Page 5:

Owen Blake - photo provided by the Stettler Independent  
ALS Snow Hut - photo provided by the Lethbridge Herald