



### ALS Society of Alberta Mission Statement

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

**Thank you** to all of our dedicated and caring volunteers. We would not be able to offer such care and support without your help.

We welcome article contributions from the public. To make a written contribution to Prairie to Peak, please submit your articles by mail, fax (403) 228-7752 or e-mail at [p2peditor@alsab.ca](mailto:p2peditor@alsab.ca). If you do not have email access, please contact Rahael at (403) 228-3857 to make alternate arrangements.

Due to limited space articles may not be printed in their entirety. Additional articles may be published online at [www.alsab.ca](http://www.alsab.ca).

### Contact us:

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## 2009 Walks for ALS!

Join us at the Alberta Walks for ALS at a location near you!

### Calgary

Sunday June 14  
North Glenmore Park  
Contact: hotline - 403-297-0569  
[www.bettysrun.ca](http://www.bettysrun.ca)

### Camrose

Saturday June 20  
Mirror Lake Park  
Contact: Nana - 780-905-5004  
[camrosewalk@alsab.ca](mailto:camrosewalk@alsab.ca)

### Cold Lake

Saturday June 13  
Lakeland Lutheran Church  
Contact: Michelle - 780-639-2360  
[coldlakewalk@alsab.ca](mailto:coldlakewalk@alsab.ca)

### Edmonton

Saturday June 13  
William Hawrelak Park  
Contact: Susan - 780-644-5996  
[edmontonwalk@alsab.ca](mailto:edmontonwalk@alsab.ca)

### Lloydminster

Saturday September 12  
Bud Miller Park  
Contact: Colleen - 780-875-1005  
[lloydminsterwalk@alsab.ca](mailto:lloydminsterwalk@alsab.ca)

### Manning

Saturday June 13  
Lion's Club Park  
Contact: Sandra - 780-836-3505  
[manningwalk@alsab.ca](mailto:manningwalk@alsab.ca)

### Medicine Hat

Saturday June 6  
Strathcona Island Park  
Contact: Katie - 403-529-8851  
[medhatwalk@alsab.ca](mailto:medhatwalk@alsab.ca)

### Red Deer

Saturday June 6  
Little Chief Park  
Contact: Greg - 403-342-8153  
[reddeerwalk@alsab.ca](mailto:reddeerwalk@alsab.ca)

For more information and to create your own fundraising website go to [www.walkforals.ca](http://www.walkforals.ca) or [www.bettysrun.ca](http://www.bettysrun.ca)



Calling all **volunteers!!** If you are interested in volunteering at any of our upcoming events or Walks, please contact Yulia at 403-228-3857 or [yulia@alsab.ca](mailto:yulia@alsab.ca) or Phyllis at 780-487-0754 or [phyllis@alsab.ca](mailto:phyllis@alsab.ca)

## Upcoming Events

### Lloydminster Dinner and Silent Auction

Saturday April 25

Come out to this delicious night filled with tons of great items to bid on!

Contact Linda Allen for tickets: 780-875-8513

### Flatiron Restaurant Dinner (Calgary)

Date TBA

Join us for a special formal dinner prepared by acclaimed chefs Noble and Blanchett.

Contact Katie for tickets: 403-262-5819

### Bo's Bar and Grill Charity Dinner (Red Deer)

Saturday May 9

Join us for a gourmet charity dinner at Bo's Bar and Grill prepared by Bo himself!

Contact Bo for tickets: 403-309-2200

### Annual General Meeting (Calgary)

Please join us at our AGM on Saturday May 23 at the Calgary office. Please RSVP to Bonnie at 403-228-3857 by May 15.

### Lilac Festival (Calgary)

Sunday May 31

Come visit our booth at the annual 4th street day festival!

### Edson IGA Fundraiser (Edson)

Saturday June 6, Edson IGA

Come on out to this great family day! There will be a BBQ, raffle and kids' carnival!

Contact Shirley for details: 780-723-3753

### Markapalooza (Calgary)

Saturday June 6, 8pm, Wild Ginger Restaurant

Join Mark as he celebrates his birthday in style again!

Contact Mark for tickets: 403-710-0093

### Tuesdays with Morrie Play (Calgary)

June 7-13

Come see this great production at the Motel theatre in the Epcor Centre. Go to

<http://fractureafemur.com/theatrical/> for more details!

### Gerrish Family Dinner (Calgary)

Friday June 12

Come out to the Canadian Danish Club to enjoy a wonderful buffet, bid on great silent auction items and meet new friends and families.

Contact Holly for tickets: 403-242-5024

### Charitee Golf Tournament

Monday June 22

Join us for the 7th annual tournament for ALS at Pinebrook Golf and Country Club.

Contact Rahael to register: 403-228-3857

## Past Events

**Belgo Fundraiser** - Thank you to Katie Wright for putting on a great night of wonderful food and fantastic silent auction items!

**Edmonton Walk Kick Off** - The Edmoton Walk committee did a superb job of organizing a impressive kick off event complete with door prizes and great company! A special thanks to Mary Ann Ellenwood for making such a compelling and emotional speech.

**Action ALS Gala** - Thank you to Maya Atallah for organizing a sensational formal gala featuring incredible dancers, delicious food and even a fire alarm in the middle of the event to make it interesting!

## Thank you to our donors!



## Eye Gaze Communication

Even for the most advanced forms of ALS, there are many communication options available. At the 2009 ALS Association's Clinical Conference in Newport Beach, California, many effective options were presented.

### Communication options for those with limited movement...

- "Yes" / "No" questioning
- Low-Tech eye gaze boards (like EyeLink or E-tran boards)
- Communication boards (letters/words/pictures) used with partner assisted scanning
- Electronic eye gaze systems
- Speech Generating Device with switch access

One session in particular reviewed eye gaze communication; systems that allow people who can't talk or move, to effectively communicate with their eyes. There are a number of systems on the market, each with different features.

Of note was a new product by Megabee: an electronic, hand-held E-tran with text output. It's portable and does not require a computer for basic operation (however it does have Bluetooth capabilities for data transfer). Eye gaze is used to determine letter locations, which are then displayed on an LCD screen. It does not require calibration. See <http://www.amdi.net> for more information.

### There are also a number of High-Tech Eye Gaze Systems on the market...

- Dynavox's "EyeMax"
- MyTobii P10
- Quick Glance
- ERICA
- LC Technologies "Eyegaze Edge"

These systems are designed for people who cannot access a computer or communication device through other methods i.e. mouse, switch scanning, etc. Eye movement is used to operate the device, enabling the person to communicate, control their environment (like operate a TV, DVD player, etc.), run computer software, and access e-mail and Internet.

Augie Nieto (Founder of Life Fitness & person w/ALS) was at the ALSA conference, demonstrating his success in using the EyeMax from Dynavox. He noted that because of this disease, he knew he would lose his voice but he did not want to lose his identity. This device has given him the "power of hope" and has kept him from feeling isolated. Take a minute to view his success video at <http://www.dynavoxtech.com/community/success/video-nieto.aspx>

### Each system has its advantages and disadvantages...

Eye gaze systems are integrated (i.e. communication + computer) & progressive and offer an alternative access method to technology for those with limited movement. However, their effectiveness can be influenced by:

- Cognitive, visual & physical abilities of user
- Age/mood/level of fatigue/state of health of user
- Lighting conditions
- Positioning of the user and system
- Portability & mounting of system
- Calibration process & amount of external assistance required



### Is Eye Gaze appropriate for you?

These systems have grown in popularity over recent years because of the progression in technology. Despite this, high-tech eye gaze is not for everyone; one must keep in mind their specific needs. What works for one person may not be ideal for another. A comprehensive assessment with your Assistive Technology Specialist is recommended to determine the most effective and efficient communication system for you.

## Resources

**Twin Cedars Villa**, located near the U of A Hospital, provides overnight accessible accommodation at reasonable rates; \$40 per night or \$60 (suite) or \$120 (whole house).

Resources for Caregivers also available at:

Twin Cedars Villa

10721-75 Ave Edmonton, AB T6E 1J8

Contact: Alberta Pasco at 780-434-0242

e-mail: alberta\_pasco@yahoo.ca

### **Pilgrims Hospice - Edmonton - Day Program**

Provides the opportunity for persons living with a life threatening condition to experience a regular day out, in a very social and warm atmosphere. The program has no formal agenda, except to just 'be', with a tasty lunch provided. This benefits you as well as your caregiver, who can reenergize during this time.

Contact Jeanne Weiss RN at 780-413-9801 x 305

### **Alberta Health Services - Capital Health**

#### **Alberta Caregiver College**

This is a virtual college that teaches Caregivers to meet the needs of a loved one with an injury, illness or disability. Caregivers can be parents, spouses, other family members or friends. Materials have been developed by Health Care Professionals from the Glenrose Rehabilitation Hospital and are specifically designed for Caregivers.

For more information call Glenrose Rehabilitation Hospital at 780-735-7999.

**William Watson Lodge** in Kananaskis Country has been designed with special features to allow people requiring a barrier free facility overnight stays in a wilderness setting. For bookings and details call 403-591-7227

## Upcoming Support Groups and Open Houses

### **ALS Spouses Group**

The ALS Spouses Group is a group of individuals whose spouses have ALS or have had ALS, who get together and support each other in their journey. The group is informal and offers support, guidance, problem solving and friendship. If you are interested in connecting with other spouses who understand your situation please contact Holly Gerrish at hgerrish@shaw.ca for more information.

### **2009 ALS Support Groups - Calgary**

Saturday, May 3, 1:30 - 3:00 p.m.  
ALS Society of Alberta office,  
Suite 400, 320 - 23 Avenue SW,

### **2009 ALS Support Groups - Red Deer**

Saturday, April 18, 2009 1:30 - 3 p.m. Plans are underway for another meeting in July.  
MS Society Office,  
105, 4807 - 50th Ave, Red Deer

### **2009 PLS Support Groups - Calgary**

Thursday, June 11, 1-3 p.m.  
Renaissance at North Hill Mall  
Condominium Complex  
1718 - 14th Avenue NW

### **2009 Edmonton Open Houses**

Held every third Tuesday of the month from 1.30 - 3.30 pm at the Edmonton Office - 410, 11456 - Jasper Ave. Call (780) 487-0754 for details. April 21, May 19, June 16

*Although we do not have specific topics for most meetings in Red Deer and Calgary at the moment, you can contact Jane at jane@alsab.ca or 403-714-8211 to see what the topic will be.*

For any questions about groups, please contact Jane. Also, if there is inclement weather, please give Jane a quick call to make sure that the group is going to happen. Blizzards, hurricanes and tornados will most likely force a cancellation of group! All support groups bring together people living with ALS, their spouse, families and friends in a caring supportive atmosphere to share the challenges and triumphs in living with ALS.

## Condolences

Our sincerest condolences go out to the families of the following people who recently passed away: January 21, 2009 to April 15, 2009

Nighat Butt

Alida Bakker

Deb Chapman

Murray Donaldson

Christine Fewster

Barbara Hurrell

Shuet-Key Lee

Kathy Matheson

John Palsgrove

Stan Paulson

Leslie Pinard

Harvey Rondeau

Elsie Seitz

Ubie 'Marc' Tougas

A special thanks goes out to all 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.