



### Coming up:

Come support the Benefit For Hope - February 7. Belgo Restaurant, Calgary. Enjoy a night of appetizers, drinks and a great silent auction! Tickets - \$40.

Edmonton Walk Kick off luncheon! March 17, 2008 at the West End Seniors Activity Centre  
11:30 am - 1:00 pm  
Confirm Attendance contact Phyllis at 780-487-0754 or e-mail: phyllis@alsab.ca

Plans are already underway for the 2009 Walks! If you would like to start a Walk for ALS in your area, or volunteer for a Walk please contact Rahael at (403)228-3857

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. If you do not have email access, please contact the Editor 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).

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## Research Projects and Updates

### Research at the U of A

Stuart Cleary is a speech-language pathologist and board-certified swallowing therapist who is an assistant professor in the Faculty of Rehabilitation Medicine and an adjunct assistant professor in Neurology at the University of Alberta.

He works in the ALS clinic at the University Hospital and is completing his PhD, in the area of breathing and swallowing treatments for people with ALS. He has three lines of research that he is conducting as part of a team at the University of Alberta, Misericordia Hospital and Cross Cancer Hospital.

First, his primary project involves studying the effects of lung volume recruitment (LVR) on the swallowing and airway clearance abilities of people with ALS. LVR is commonly used by people with ALS, yet little is known about how well it works. This project is ongoing.

The second line of research is focused on the outcomes of treatments for drooling and management of thick secretions. One method to control drooling is radiation therapy to saliva glands. Stuart is interested in the impact of such treatment on swallowing and quality of life.

Additionally, Stuart is starting a study in which he is looking at the effects of the use of a hand-powered suction pump to clear thick secretions from the mouth to aid in oral hygiene.

Stuart's third line of work will be focused on the effects of non-invasive ventilation, or BiPAP, on speech, voice, swallowing, and breathing function of individuals with ALS.

Stuart can be reached at (780) 492-5238 or [stuart.cleary@ualberta.ca](mailto:stuart.cleary@ualberta.ca)

### Quirk Research Fellowship

In April 2008, the Quirk fellowship was created in order to further research into ALS. The first recipient of this fellowship was Dr. Mathieu Chansard, who will be studying in the labs of Drs. C. Toth and M.D. Nguyen at the Hotchkiss Brain Institute at the University of Calgary.

Although many researchers have attempted to decipher the mechanisms that lead to the specific loss of motor neurons in ALS, none have been successful to date. Nevertheless, these studies have allowed us to draw a fairly detailed picture of what malfunctions in targeted neuronal cells.

Among the different cellular abnormalities observed, it has been shown that the intracellular trafficking that mediates the transport of essential signals is impaired in these motor neurons. This means that important proteins that enter the motor neuron at an extremity, like proteins involved in neuronal survival, will never be successfully transported along the cellular skeleton (cytoskeleton) to the nucleus of the cell, where they usually play their role.

The research associated with the Quirk fellowship focuses on identifying the actors involved in these intracellular trafficking dysfunctions. The researchers have identified a novel molecular complex that is constituted of a protein known to organize the cytoskeleton and proteins involved in the early steps of intracellular trafficking. They have also gathered preliminary data suggesting that all components of this protein complex modulate intracellular trafficking.

Although these findings are preliminary and remain to be confirmed, they imply that this novel molecular complex could be involved in ALS and pave the way for additional research.

## Message from the Executive Director

2008 was an exciting year for the ALS Society of Alberta. Some of the highlights included:

- our five year strategic plan was finalized and approved by our board of directors,
- we held our first annual long term employee and volunteer recognition in Calgary and Edmonton
- once again blessed by our volunteers across Alberta we raised significant resources for the Society's client services and equipment program.
- We contributed \$356,000 to ALS Canada for much needed research.
- We financially supported the lung volume recruitment study at the University of Alberta.

As we move forward into 2009, we will move with some uncertainty as to how the economic climate will affect us. Although this uncertainty exists, we are committed to our five year strategic priorities that will guide us over the next five years. Our plan is to continue to seek feedback from our stakeholders and make every day the best possible day for people living with ALS.



Karen Caughey, Executive Director

## Happy New Year!

We wish you and your family all the best in the year to come, from all of us here at the ALS Society of Alberta.



## Volunteer Recognition

Thank you to everyone who attended our first ever volunteer recognition and long term employee events in Calgary and Edmonton. They were both huge successes. Congratulations to Jane Rivest and Patricia Ordynec who received long term employee recognition.

Thank you also to all of our dedicated volunteers who help so much throughout the year. We would not be able to do what we do without your help and support.

If you are interested in volunteering with the ALS Society of Alberta, please contact Yulia, Volunteer Coordinator at (403) 228-3857 or Phyllis at (780) 487-0754 for Edmonton Volunteering.



## Welcome!

Please join us in welcoming two new staff members to our team. In September 2008, Bonnie McKitrick stepped in as our new Office Coordinator, as Yulia Eskin accepted a new and challenging role as Volunteer Coordinator. Starting our new year off right, we have also brought in Jeremy Wojtkiw as our new Equipment Program Coordinator. Welcome to the 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 with ALS by providing support, facilitating the provision of care, promoting awareness and helping find a cure."*

## Tips and Tricks

### Shower Exposed Valve manufactured by GROHE

One of our families has installed a shower exposed valve in their renovated bathroom which has allowed them to permanently set the volume and the temperature of the water coming out of the tap. This had made bathing and showering a much easier process than it was before this was installed. These items can be purchased or ordered from plumbing supply stores.

### Nail Clippers

Nail clipping can become a big challenge for our clients. Nail clippers (seen at local vendors) can be purchased already stuck onto a board so that you can lean on the clipper portion with the palm of your hand. The small board also has an emery file attached. You can also purchase nail clippers that clip from the side of the clipper. These have been purchased at a local Coop Store, and also seen at local drugstores and vendors.



### Library Books

Have you been scanning your book shelves lately and wondered where you got those books on ALS - 'Tuesdays with Morrie', 'Laugh I thought I'd die?' for instance. Would you mind having a look on your shelves to check to see if any of these books belong to the ALS Society of Alberta? You can either pop them in the mail, or return them when your Client Service Personnel comes for a visit, OR bring them to Clinic and

return them to the ALS Society staff member who might be there. Thank You!

### Alarm Care (suggested by somebody at support group - worth checking out!)

AlarmCare is designed for people seeking more independence and security in their lives, and of course for anyone who may need help in the event of an emergency. It also provides your loved ones with the peace of mind of knowing that you are always connected to help and never alone. If you know someone who could benefit from this

added element of comfort and security, please call today and one of our friendly consultants will gladly answer all of your questions with no pressure or obligation.

Phone 1-800-267-2001 or check out the web site [www.alarmforce.com](http://www.alarmforce.com) and then click on AlarmCare. Many of our clients also use Lifeline, which is a similar service. They can be reached at [www.lifeline.ca](http://www.lifeline.ca) or 1-866-784-1992.

### Tax Info - 2008

Disability Tax Credit provides a tax reduction of up to \$1,053. to individuals who have a severe physical impairment. Also, if travel is required for 40K or more, you can claim this mileage plus meal allowance. Keep the receipts. There is caregiver credit of up to \$614.00 for low income individuals. For more information see Human Resources Social Development Canada - Advancing the Inclusion of People with Disabilities 2008.

### Capital Health Information

Community Rehabilitation Interdisciplinary Service (CRIS) Helps people with complex rehabilitation to remain independent in the community. For more details call 780-735-2413 or 780-413-7609.

### Twin Cedars Villa Alberta Centre for Family Caregivers

10721 - 75 Street, Edmonton, AB T6E 1J8

The centre provides accessible accommodation for persons/family/caregivers visiting Edmonton from out of town, mainly for medical appointments. It provides family and caregivers with information and referral, life skills training, respite from care-giving, support and linkage with others "who have been there" or who "are willing to be there" with 3 goals:

1) to relieve stress 2) to enable family caregivers to respond to the needs of their disabled loved ones 3) to enhance the quality of their own lives in the process.

### Hope Air

Hope Air is a national charity that helps Canadians get to medical treatment when they cannot afford the flight costs. Since 1986, Hope Air has arranged more than 53,000 flights. Here is a link to their website: <http://www.hopeair.org>

Thank you to our donors!



### Third-party Events

#### Extreme racing for ALS

"Friendship, hope and strength" are essential tools in the fight against ALS. They are also what brought a group of people together to support their good friend, upon hearing of his ALS diagnosis. Steve Barker, Barry Kraft, Greg Robins, Cam Nichols and Chris Breen, from Edmonton and Sherwood Park, decided to form a team and enter the Canadian Death Race. And so, 'Saz's Soldiers' was born.



The Canadian Death Race is one of the world's more challenging adventure races. Participants run a 125k course that passes over three mountain summits and across a major river crossing at Hell's Gate canyon. Saz's Soldiers entered the race with a passionate commitment towards raising funds for research in finding a cure for ALS.

Held over the August long weekend, the team made it through with a time of 18:22:41 and more than a few bumps and bruises. Their community came together to support the cause, with Spartan Controls hosting a BBQ and raising money through their annual golf tournament. A local business pitched in as a sponsor, t-shirts were sold and online donations came in strong to support the team.

With an original goal of raising \$10k for the ALS Society of Alberta, their hard work and fundraising efforts brought in \$24,780. Thanks to this small group with a big idea, the race was extremely successful in raising both funds and awareness of ALS and the hope for a cure.

**A huge thanks to our other third party events:**  
**Big League Apparel Silent Auction and Dinner** - Brian Eaglesham  
**Silent Auction and Dinner** - Tony Gize  
**From the Heart Silent Auction and Dance** - Linda McMurray

### 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, January 10,  
 February 7, March 7, April 4  
 1:30 - 3:00 p.m.  
 ALS Society of Alberta office,  
 Suite 400, 320 - 23 Avenue  
 SW, Calgary

#### 2009 ALS Support Groups - Red Deer

Saturday, February 21, 2009  
 (topic: advance care planning)  
 and Saturday April 18, 2009  
 1:30 - 3 p.m.  
 MS Society Office,  
 105, 4807 - 50th Ave, Red  
 Deer

#### 2009 PLS Support Groups - Calgary

Thursday, February 5 1-3 p.m.  
 Renaissance at North Hill Mall  
 Condominium Complex  
 1718 - 14th Avenue NW  
 Guest Speaker: Barry Devolin  
 SLP with the Calgary Health  
 Region. Barry will speak on  
 speech changes in PLS.

#### 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.

*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: August 22, 2008 - January 20, 2009

|                   |                  |                  |                   |
|-------------------|------------------|------------------|-------------------|
| Jim Beattie       | Lois Jensen      | Donna Paterson   | Dale Sheppard     |
| Joy Bilozir       | Leonard Lawrence | Dennis Paulson   | Leslie Smith      |
| Lawrence Campbell | Gordon Look      | Marjorie Ptolemy | Wayne Stevenson   |
| Cicely Hargreaves | Douglas Luckwell | Judy Reader      | Freda Strohschein |
| Dorothy Hart      | Donald Mattice   | Tom Reed         | Ella Vrkljan      |
| Joe Hodgson       | Duncan MacDonald | Lawrence Sawchuk | Brian White       |
| Uwe Janssen       | Dugald McLennan  | Raymond Shannon  | Adeline Wight     |

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.