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To make a written contribution to *Prairie to Peak*, please submit your articles by e-mail to the Editor, Wayne Steer, at [wayne@alsab.ca](mailto:wayne@alsab.ca). If you do not have email access, please contact Wayne Steer 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).

### ELIZABETH'S



### CONCERT OF HOPE

A Gala Benefit for the  
ALS  
Society of Alberta

## Elizabeth's Concert of Hope

Over the past five years Elizabeth Grandbois has organized five sold-out concerts showcasing the royalty of the Canadian music and entertainment scene while bravely traveling her journey with ALS. These concerts are normally hosted in Ontario and have raised over \$1.6 million for ALS client support and research. This is Elizabeth's last year as the concert's driving force and her vision for the concert is grander than ever. For the first time in its history, the concert is spilling over provincial borders with tour dates for 10 concerts in 10 provinces scheduled for this year. The very successful Elizabeth's Concert of Hope is coming to Alberta in mid-September to benefit the ALS Society of Alberta and will boast some of our province's most acclaimed home-grown talent.

The Executive Director of the tour is none other than Kathleene Cochrane, wife of Canadian musical mega-star Tom Cochrane. The ALS Society of Alberta has amassed an enthusiastic core of concert volunteer organizers and is welcoming others to come aboard for this once-in-a-lifetime volunteer opportunity.

## New ALS Journey Book Available

Rev. Howard Lund (1946 – 2005) was a pastor, teacher, principal and writer. He was diagnosed with ALS in August 2004 and has now completed his journey, in faith. He was a father to four, grandpa to eight and husband to Ann who lives in Edmonton.

Howard has written the story of his journey with ALS called "Walking through the Valley - Dealing with the prospects of Death with Bulbar ALS". This is available to pre-order at the website [www.lulu.com/howardlund](http://www.lulu.com/howardlund). His second book, "The Stained and Wrinkled Church", is also available on this site.

### 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."

## RESOURCE DEVELOPMENT

### First Steps for 2006 Walks for ALS



The ALS Society of Alberta is once again preparing for another busy June in which up to ten Walks for ALS are anticipated to be organized across Alberta. The majority of

these Walks for ALS will take place on Saturday June 10, 2006. To volunteer to help organize a Walk for ALS in your area, call Wayne Steer at 228-3857.

The organizers of the Edmonton Walk for ALS have begun their planning for the 2006 event and are seeking sponsors to supply a variety of equipment (tents, sound system, tables, chairs, podium, etc.) If your business is interested in becoming a sponsor or if you know of a business that may be interested, call (780) 487-0754. It is only with the collective effort of community sponsors that we can keep our expenses low so that the most benefit is harnessed from every dollar that this major fundraising event garners.

For more information on becoming involved in a walk in your area, contact Wayne Steer at (403) 228-3857 or toll free at 1-888-309-1111 or e-mail [wayne@alsab.ca](mailto:wayne@alsab.ca).

### ALS Bracelets

Demand has been steady for the recently introduced purple silicon ALS bracelets. To receive yours call 228-3857 (outside the Calgary calling area call toll free 1-888-309-1111) or email Wayne Steer ([wayne@alsab.ca](mailto:wayne@alsab.ca)) and arrange to have them mailed or picked-up directly from the office to save on postage charges. The bracelets are selling for a minimum donation of \$3 and are a wonderful tool for raising awareness and creating solidarity within the ALS community.

Mike Shirley is credited with the creativity behind the wording that was chosen for the bracelets: "ALS Its About Loving Someone". The bracelets also are debossed with two of the Society's logos that flank the ALS Society of Alberta's website.

### Supporting Youth Affected by ALS

In the fall edition of *Prairie to Peak*, it was mentioned that a new program had been established to help the children and teenagers of people with ALS to have more normal childhoods.

This funding will be used to pay for such things as

uniforms, camp registration, event tickets, etc. Our hopes are that one day, the program will become big enough to provide brighter futures through scholarships for children affected by ALS.

### Betty's Run Committee is Warming Up for a Record Year



The Betty's Run for ALS Committee is well on their way to another successful year. This is a benchmark year for the event as it will be Calgary's tenth annual run and walk fundraiser in honour of the memory of Betty Norman.

The organizers this year plan on an event that is bigger than ever and are hoping for record participant turnout, corporate support and fundraising successes.

To volunteer your efforts before or during the event contact Jane Rivest at 228-3857 (extension 102). The event will be held on June 11, 2006 at the North Glenmore Park in Calgary. There are many different volunteer roles that make this event a success including organizing the entertainment before and after the run and walk, route marshals, registration volunteers, food service volunteers, sponsor relations and entertaining children in the Kids Tent.

For more information about the tenth annual Betty's Run for ALS, visit the official run website at <http://www.alsab.ca/events/bettysrun.aspx>.

### Direct Mail Campaign

Recently ALS AB embarked on its first targeted direct mail campaign, which has been very successful in many respects.

This was a way for ALS AB to thank many of those who had contributed in the past through memorial donations, the Betty's Run for ALS, the Walks for ALS and in many other ways. We were also able to inform people of how their past contributions have made a difference and some of the challenges that have arisen from our growth.

A heartfelt "Thank you" goes out to all who have supported the ALS Society of Alberta in the past and to all of those who continue to support us ...YOU really do make a difference.

### Condolences

Our sincerest condolences go out to the families of the following people who have recently passed away:

Edwin Beierbach

Edna Hansen

Stanley Kobluk

Jorgen (John) Olsen

Ralph Shaner

Margaret Clavelle

Gale Hilman

Father Josaphat Konchak

Mohammed Rahim

Ron Wells

Donald Felstad

Michael Huska

Howard Lund

Oscar Rivard

Alan Ray Wilson

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.

## Executive Director's Message

Hello and welcome to the first 2006 issue of Prairie to Peak. I am looking forward to a year that will continue to expand the ability of ALS AB to "...make everyday the best possible day for people with ALS..."

In this issue I am very pleased to introduce you to Wayne Steer, Manager, Resource Development and Cindy Deslaurier, Senior Staff Assistant.



**Wayne Steer**  
Manager, Resource  
Development

Wayne has been with ALS AB for a little over a year now and is responsible for all aspects of fundraising including providing support to all events (such as walks, runs, concerts, etc.), Planned Giving and Donor Campaigns. Wayne is also responsible for the ALS AB website.

From the tender age of six months, Wayne has developed deep roots in Calgary but has lived, worked and volunteered in other communities

including Edmonton, Lloydminster and Fort McMurray. Wayne also takes a very active role in the AFP (Association of Fundraising Professionals) in Calgary. Thank you Wayne for all your efforts, ensuring ALS AB has the resources needed to provide both equipment and services to those in Alberta and NWT living with ALS.



**Cindy Deslaurier**  
Senior Staff Assistant

Cindy Deslaurier first came to ALS AB as a summer student in May of 2005. Cindy is just finishing up a Bachelor of Applied Nonprofit Studies degree at Mount Royal College and, at the end of last summer, agreed to stay on as a part-time staff member. Her role is loosely defined as Senior Staff Assistant and she is fully capable of turning her hand to a wide variety of tasks, helping Wayne develop funding proposals,

supporting clients by getting information out in a timely manner or working with volunteers.

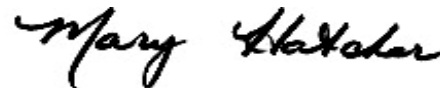
Cindy's time with ALS AB will be coming to a close at the end of April as she must leave us to complete her final practicum at another agency. Cindy will be sorely missed. Thank you Cindy, for all you do. You are a real asset to the non-profit sector in Calgary and we wish you the very best in your continued growth in and enrichment of the sector.

2006 is shaping up to be a very active one for ALS AB. We continue to grow, in the numbers of people we serve, in the numbers of volunteers and staff who implement the programs, in the dollars raised to support the work and in the programs and services we can provide. Over the next few months we will be growing physically as well, as the Provincial Office expands into the vacant space right next to our current offices.

Also check out the upcoming activities and events noted in this issue and mark them in you calendar.

Together, we do make a difference.

Thank you,



## Advocacy Project Update

In 2004 the ALS Society of Alberta (ALS AB) had the opportunity to present the results of a Client Survey at a very successful 'Day at the Legislature'.

During the fall of 2004 a presentation was made to the Government of Alberta's Standing Policy Committee on Health - a committee comprised of Alberta MLAs that oversees and influences policy reviews and decisions for areas related to Health and Wellness. A second presentation is scheduled for February 2006 where further developments will be shared. Our dialogue with the government continues.

In 2005 ALS AB worked in conjunction with provincial ALS specialists to strategically craft and send ALS information letters to each family physician in Alberta. Preliminary feedback indicates that the mail-out has successfully met its objective of heightening physician awareness and it promises to result in a greater number of early referrals to specialists for accurate and timely diagnoses.

Further, this initiative will bolster prompt client access to medical management support through the ALS Clinics as well as increasing the visibility of the programs and services offered by ALS AB. ALS AB supports and participates in multi-disciplinary care and recognizes that it has an immensely positive effect on the well being of people living with ALS.

The mail-out campaign targeting medical specialists will be completed by early 2006 and upon completion over 4,000 people in the medical community will have been provided this important message.

The Advocacy Committee is committed to providing a persuasive voice for Albertans who are affected by this devastating disease. Advocacy is an important way in which ALS AB can be a progressive change agent as we strive to fulfill our mission to make "... everyday the best possible day for people with ALS..."

If you are interested in becoming involved with the ALS Society of Alberta's Advocacy Committee please contact Cathy Martin at (780) 463-4905 or e-mail [cathy@alsab.ca](mailto:cathy@alsab.ca).

## Clinical Research on Familial ALS

Researchers at the ALS Center at Emory University are investigating the possibility of designing a clinical trial for persons at risk for familial (inherited) ALS. Since this is a rare disease, the researchers indicate that their first step is to determine the number of persons who might be eligible for such a study, and whether these people might be willing to participate in the study.

The research team is searching for families where two or more family members have or had a diagnosis of ALS. Dr. Jonathan Glass, the principal investigator of the research, tells ALSA that they are particularly interested in identifying healthy members of these families that may be at risk for developing ALS. The initial contact will consist of a telephone conversation, lasting 10 to 20 minutes, during which investigators will ask questions about the individual's health and the family history. Those persons at risk will be questioned as to their potential interest in participating in a clinical trial aimed at preventing or delaying the onset of disease.

The researchers indicate that, based on the initial telephone conversations described above, a second study may follow that would include a treatment trial to evaluate compounds intended to prevent or delay the onset of ALS in at-risk individuals.

If you believe you have familial ALS or may be at risk for familial ALS (two or more family members with ALS), and you are interested in learning more about this study, please call The ALS Center at Emory University toll free at 888-413-9315. The contact person is Meraida Polak, RN, ALS Research Nurse.

## Hints from Clients and their Families for Clients and their Families

We welcome any hints that clients or their families can offer to others within the ALS community regarding ways to overcome or otherwise cope with challenges faced during the journey with ALS. Sharing your knowledge may make someone else's day brighter and easier. Please email hints and suggestions to Jane Rivest at jane@alsab.ca.

Information such as dentists, hairdressers, foot care specialists and any other service provider who are willing to make home visits may be very valuable to others in your neighbourhood or region.

## Out and About - Around the Province

The support groups and education sessions offer a time for people who are traveling this ALS journey to share ideas and receive support and information from each other. People living with ALS, their families and caregivers are all welcome.

### Calgary Saturday Support Group Meetings:

**When:** Saturday February 11 (1:30 to 3 pm)  
Saturday March 11 (1:30 to 3 pm)  
Saturday April 8 (1:30 to 3 pm)  
Saturday May 6 (1:30 to 3 pm)

**Where:** ALS AB Office at 400, 320 – 23<sup>rd</sup> Avenue SW  
**Facilitated by:** Jane Rivest and Laura Cavicchi, Social Worker, will facilitate all support group meetings. The session topics will vary. To find out the topic for a particular session contact Jane Rivest.

### Red Deer Saturday Support Group Meetings:

**When:** Saturday March 4 (1:30 to 3 pm)  
Saturday April 29 (1:30 to 3 pm)

**Where:** MS Society Office at 4322-52 Avenue Red Deer

**Facilitated by:** Jane Rivest and/or Patricia Ordynec will facilitate all support group meetings and may be joined by a guest speaker. The session topics will vary. To find out the topic for a particular session contact Jane Rivest.

### Edmonton Education Sessions:

**What:** It's About Loving Someone

**When:** Wednesday February 15 (3-7pm Open House)

**Where:** Suite 410, Jasper Centre 11456 Jasper Avenue Edmonton

**Why:** To celebrate Alberta Caregiver's Week and to introduce the ALS AB "It's About Loving Someone" Bracelets

**Look for future announcements regarding spring education sessions to be hosted in Edmonton.**

## Thank-you to Santa's Helper

On Friday December 23, 2005 the ALS Society staff was surprised with a special gift from a friend of one of the Calgary office's regular volunteers. This volunteer had casually mentioned to her friend months ago that the microwave in the kitchen of the office was ancient and dreadfully slow. Her friend remembered that comment and scouted for a more reliable appliance for the office and donated a new one as a Christmas gift.

This thoughtful act touched each and every staff member. We would like to extend a heartfelt thank-you to this thoughtful Santa's Helper. We are truly thankful for this generous, and very unexpected, donation and the staff are now enjoying our hot lunches the way that they are supposed to be – hot!

## Alberta Family Caregiving Week

Do you provide assistance or support to a family member, friend, or neighbour who has a chronic illness or disability? If you do, then you are a family caregiver. If you are not a family caregiver, chances are you know someone who is.

At some point in their lives, most people will be affected in some way by family caregiving. It has become more than an act of love and familial responsibility as it is now an essential element of our healthcare system. As Canadian writer David Silver Cameron so aptly stated, "if Canada's healthcare system were a plant, family caregivers would be its roots: invisible, fragile, and vital".

The Alberta Caregivers Association (ACA) and its supporting organizations are proclaiming the first Family Caregiving Week in Alberta from February 12 to 18, 2006. We hope to raise awareness of family caregivers in our province in order to honour these important people and their vital contributions to a healthy Alberta.

The ACA and its members are promoting awareness of Family Caregiving Week by encouraging groups to organize special events and by distributing "Caregiving Cards" that will help people support family caregivers that they know. These cards represent gift certificates that offer the time and assistance of those who want to help.

To find out more, contact the ACA at (780) 447-9301 or e-mail [admin@AlbertaCaregiversAssociation.org](mailto:admin@AlbertaCaregiversAssociation.org).

## Growth Spurt

The ALS Society of Alberta continues to grow rapidly and 2006 will be no exception. Our office space is expanding to accommodate a change in our equipment program management system and in anticipation of the introduction of a new staff position. The Society will also use the space to better serve clients and the plans for the space will have a focus on accessibility and privacy and will be far more client-friendly than the current space. The renovations are currently underway.

## Albertan's Fundraising Efforts Earn National Recognition

Rocky Mountain House resident Terry Layden was recently recognized for his extraordinary effort he invested in fundraising for the Rocky Mountain House 2005 Walk for ALS. He raised over \$18,000 through soliciting friends, family and colleagues and by utilizing our website's ability to construct personalized fundraising websites for various events.

Terry was rewarded with a Canon Digital Camera from ALS Canada and with the knowledge that "together, we make a difference."

## ALS Clinic Doctors Honoured by the Lieutenant Governor

The ALS Society of Alberta extends enthusiastic congratulations to **Dr. Wendy Johnston** and **Dr. Sanjay Kalra** as recipients of the Alberta Centennial Medal. The Alberta Centennial Medal celebrates Alberta's first 100 years by paying tribute to Albertans whose achievements have benefited their fellow citizens, their community and their province.

Dr. Johnston and Dr. Kalra received this award on November 21<sup>st</sup> from the Lieutenant Governor of Alberta, the Honourable Norman L. Kwong, CM, AOE. The Lieutenant Governor is also the Patron of the ALS Society of Alberta. Dr. Kalra and Dr. Johnston lead the ALS Clinic at the University of Alberta Hospital in Edmonton. His Honour first met Dr.'s Kalra and Johnston at the 2005 Walk for ALS in Edmonton, and was impressed by their dedication and work. Both were later nominated for the Alberta Centennial Medal through support from the ALS Society of Alberta.

Their dedication, compassion and international expertise help those living with ALS in many immeasurable ways and we are delighted that their many contributions have been acknowledged so prestigiously.

Congratulations again on an award so well deserved!



Dr. Sanjay Kalra (left) and Dr. Wendy Johnston (right) pose with the Lieutenant Governor of Alberta, the Honourable Norman L. Kwong, CM, AOE (center) while holding their Alberta Centennial Medals on November 21, 2005



### Obverse side of the Alberta Centennial Medal

The medals are cast in bronze and plated in gold. Their simple design features the Alberta coat of arms and "Alberta Centennial 1905-2005" on the front side (shown here). The reverse side is adorned with the Alberta shield nested inside a Maple Leaf surrounded by the words "Honouring Outstanding Albertans".

## Edmonton Office: A Year in Review

The growth of the organization has been felt in both the Edmonton and Calgary offices. The Edmonton office is staffed by Patricia Ordynec (Manager) and Phyllis Javorsky (Administration and Volunteer Services) who are two very capable full-time staff members who are dedicated to "...making everyday the best possible day for people with ALS..."

Patricia from the Edmonton office recently shared some of the highlights for that office in 2005. They include the following:

- The clinics available in the North region increased to three sites including the University of Alberta, Misericordia Hospital and the Glenrose Clinic.
- The office staff members have increased their need and capacity to effectively utilize project and office volunteers.
- Well over 16,000 volunteer hours were generously contributed to many different events and projects in the north region.
- The Edmonton Walk for ALS alone raised approximately \$115,000. An additional \$103,000 was raised through this office in 2005. A more than 100% increase over the previous year.
- The Edmonton office staff and volunteers are in the midst of a large awareness and advocacy campaign that is anticipated to reach over 4000 of Alberta's medical professionals.
- A presentation was made to the Government of Alberta's Standing Policy Committee on Health and another such presentation is scheduled for February 2006.

Congratulations Patricia and Phyllis on a job well done and thank you to all the volunteers who supported you both in "...making everyday the best possible day for people with ALS..."



## Thinking about Estate Planning?

**Are you looking to enrich your heirs and minimize taxes while helping non-profits?** If so, this spring's Legacy Seminar Series may provide answers to some of the tougher questions and reveal options you had not previously considered. These seminars are hosted by Leave A Legacy™ and provide valuable information to help you start planning or fine tune your estate – there is so much more to consider than just wills.

These **FREE** public seminars will be held on May 16<sup>th</sup> and 17<sup>th</sup> at the Red & White Club at McMahon Stadium (**FREE** Parking available). Refreshments will be served but no food service will be provided.

If you are interested in receiving more information and/or an invitation, please call Wayne at 228-3857 x 108 or e-mail [wayne@alsab.ca](mailto:wayne@alsab.ca). The information you receive here could save your estate a bundle in taxes while helping worthwhile organizations.

## The ALS Society of Alberta Contact Information

The Amyotrophic Lateral Sclerosis Society of Alberta's **Provincial Office** is located at:

Suite 400, 320-23 Avenue SW,  
Calgary Alberta, T2S 0J2  
Telephone: 403-228-3857 or  
Toll Free: 1-888-309-1111  
Fax: 403-228-7752  
Website: [www.alsab.ca](http://www.alsab.ca)

### List of Provincial Office Contacts:

Helen Desjardins – Office Coordinator	helen@alsab.ca	Extension 101
Mary Hatcher – Executive Director	mary@alsab.ca	Extension 103
Lauren Milburn – Equipment Program Coordinator	lauren@alsab.ca	Extension 105
Jane Rivest – Client Services Manager,	jane@alsab.ca	Extension 102
Wayne Steer – Resource Development	wayne@alsab.ca	Extension 108

General e-mail inquiries can be sent to [info@alsab.ca](mailto:info@alsab.ca) and will be directed to the appropriate person by the Office Coordinator.

### The North Region Office is located at:

Suite 410, 11456 Jasper Avenue  
Edmonton Alberta, T5K 0M1  
Telephone: 780-487-0754 or  
Toll Free: 1-866-447-0754  
Fax: 780-486-3604

### List of Alberta North Region Office Contacts:

Phyllis Javorsky – Administration and Volunteer Services	phyllis@alsab.ca
Patricia Ordynec – Manager, North Region & Client Services	patricia@alsab.ca

General e-mail inquires for the North Region office can be sent to [societynorth@alsab.ca](mailto:societynorth@alsab.ca) and will be directed to the appropriate person.

## ALS Society of Alberta Privacy Policy

The ALS Society of Alberta (ALS AB) currently has a policy not to sell, trade or rent the names of people who communicate with or donate to the Society either directly or indirectly through events that are conducted to benefit the ALS Society of Alberta and the people we serve. From time to time ALS AB may undertake to communicate directly with those people on our database in order to thank, inform and/or communicate a specific need for volunteer, financial or other resources.

Anyone who prefers to be contacted by e-mail, please contact us by e-mailing a note to [info@alsab.ca](mailto:info@alsab.ca) with the heading "**Contact by E-mail**" on the subject line along with your full name in the body of the note.

Anyone wishing not to be included on that list may be removed from that list by either contacting the ALS AB offices at (403) 228-3857 (or toll free at 888-309-1111) or by e-mail at [info@alsab.ca](mailto:info@alsab.ca) with the word "**Remove**" on the subject line. Please be sure and provide your name and address so that we may comply with your wishes.