



Walks for ALS Break Records Once Again!

Coming up:

* Volunteer opportunities are always available through the Society. Please contact the office for any upcoming events

* Copies of the 2008 Strategic Plan are available now! Please contact the office if you would like a copy.

* Lloyminster Walk - September 13, 2008. Please contact Colleen Christie for details. (780)875-1005

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. Due to limited space articles may not be printed in their entirety.

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In June, over 1400 people came out to support the annual Alberta Walks for ALS. This year has been even more successful than last year! Over \$380,000 has been raised at the 7 walks that have already been completed, with one walk still to go in September! This was an increase of \$68,000 from last year. 40% of the net funds raised will go towards research and 60% will go towards client services and equipment in Alberta. Each Walk was filled with love, support and friendship, as people came from all over to participate with family and friends. The success of each of these Walks would not have been possible without the hard work and endless dedication from the many Walk committees in each location. These volunteers work from September to the day of, planning these incredible events. Every detail from event location to prizes and food must be seen to. Thank you so much to all the committees and volunteers who put their time and effort into making the day such a success! If you're interested in starting a Walk for ALS in your area, please contact Rahael at (403)228-3857 or rahael@alsab.ca.

Location	Total	Chair
Lethbridge	\$23,489	Marilynn Christie
Medicine Hat	\$11,850	Katie Jordison
Grande Prairie	\$38,477	Debbie Dechant
Red Deer	\$113,823	Greg LeBlanc
Edmonton	\$176,711	Susan Wright
Manning	\$14,070	Saundra Dechant
Cold Lake	\$8,051	Michelle Feduniak
Lloydminster	Sept 13, 2008	Colleen Christie
Calgary	\$531,000	Betty's Run Comm.



Another Great Year For Betty's Run!

The 12th Annual Betty's Run for ALS was held on June 14. This year was once again a true triumph! Over 1300 people came out to support ALS, despite the rain! The day was filled with great entertainment, superb food and plenty of friends. The event raised over \$530,000 for client services and research. Kevin O'Keefe, our Betty's Run 2008 Ambassador kicked the day off by biking in from Rockyford and the Calgary Fiddlers provided upbeat music for dancing the cold air away! It was a great day and the feeling of love and support in the air was palpable.

Thank you so much to the Betty's Run Committee for working so hard to make sure every detail was taken care of. The day ran extremely smoothly and would not have been possible without the help of all the fantastic volunteers.



ALS Society of Alberta Vision Statement

"Our vision is to make each day the best possible day for people living with and affected by ALS. We achieve our vision by providing support, facilitating the provision of care, promoting awareness, helping find a cure and advocating for change."



Sisters

Sisters Walking for ALS

Our sister and aunt, Connie Lonsberry passed away in December 2004. Her battle with ALS was, thankfully, a short one as she passed away 1 ½ years after being diagnosed. We miss her and know that she is watching over us everyday.

Before she was diagnosed, none of our family really knew anything about ALS. The ALS Society was very helpful in answering questions and providing excellent support for Connie and the rest of our family. They ensured that Connie received the best possible care.

For this reason, we decided to put together a team and participate in the ALS Walk held in Lethbridge, Alberta. Participating in the walk has given us a chance to honour Connie while at the same time help raise funds for the ALS Society.

Our team of seven traveled from 3 different provinces to attend - Manitoba, Saskatchewan and Alberta. "Sisters" is made up of 2 of Connie's sisters and 5 of her nieces. Even with the cold, wet and cloudy day, we had a great time.

We would like to thank the organizers, as well as the ALS Society for all their planning and hard work to make this walk the success it was. We look forward to participating again next year.

Marlene, Mary Lou, Cindy, Jackie, Dianne, Carrie and Jennifer

Kevin's Ride for ALS

Kevin O'Keefe was named this year's Betty's Run Ambassador, and took up the challenge with energy and enthusiasm. Kevin, who lives in Rockyford, decided to bike from Rockyford to Calgary to kick off the run this year. He took three days to bike, and arrived right on time at the opening of the Betty's Run ceremonies. Kevin was accompanied by his two children and his long time friends. He was also escorted by a large mobile home with a large banner for Kevin across it. The entourage of people were hard to miss flying down the highway!

The town of Rockyford could not have been more supportive of Kevin's Ride. Rockyford elementary school held a pancake breakfast in his honour on the morning of his departure, which was not only well attended, but also delicious!

Kevin lives in Rockyford with his wife Dixie and his two children, who both biked with him. He was diagnosed in 2007 and continues to live life to it's fullest.

Kevin raised almost \$10,000 for Betty's Run and spread endless awareness about ALS. He still continues to be dedicated to spreading the word about ALS and the hope that there will soon be a cure.



Kevin and his children Miles and Courtney

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, anthropologist

Third-party Events

Thank you to the following third party supporters:

Great Canadian Death Race – Chris Breen
Howard Smith Memorial Calf Roping – Rosalie Smith
Bo's Charity Dinner – Bo
Charitee Golf Tournament – Charitee Committee
Markapalooza – Mark Hopkins
Gerrish Family Dinner – Holly Gerrish
Linford Foods - Keith Linford

Notre Dame Silent Auction – Celeste Bazinet
Chili Cook Off – Joy Bilozir
North Cooking Lake Community Association
Spartan Controls - Golf Tournament – Chris Breen
Edmonton Bridge Centre - Matthew Greenways
Abal Building Products - Golf Tournament
Thanks to all our casino volunteers!



Incredible body painting at Markapalooza



SAZ's SoLdierS Death Race Team



Howard Smith Memorial Calf Roping

Upcoming Events:

Buffet and Silent Auction:

Come join us at Bonanza Western Grill (12536 - 137 Ave. Edmonton) on October 7, 2008 at 5pm. Tickets are \$24.99 for adults and \$11.99 for children under the age of 11. For tickets call (780)990-1010 or visit event sponsors - Big League Apparel Sports or Bonanza Western Grill

From the Heart:

Come support the second annual From the Heart, silent auction and entertainment night at Good Shepherd Church - 6311 Norfolk Dr NW, Calgary. October 11, 2008 at 8pm. Tickets are \$30 and can be purchased by calling (403)256-5647 or (403)651-1002

Equipment Highlight

Over the years, the ALS Society of Alberta's provincial equipment program has grown vastly to continually provide vital equipment to those living with ALS.

This equipment includes, but is not limited to; power wheelchairs, hospital beds, porch lifts, ceiling tracks, high end mattresses, ramps and commodes.

Over the last few years, demand for equipment has risen steadily. In 2005 the Society provided 33 power wheelchairs, in 2007 the number grew to 46 and already 26 wheelchairs have been loaned out this year. The number of requests for porch lifts has also increased over the past few years. Porch lifts enable people to stay in their homes. In 2005 we provided 10 porch lifts. In 2006 the number grew to 21 and already this year we have provided 25 porch lifts to those who need them.

The Society not only provides the equipment, but also works with families and insurance companies to fund the equipment, ensuring that any funding shortfall is taken care of. We maintain a pool of equipment across the province so that at any point a needed piece of equipment can be made available to those who need it.

The large sums of money required to pay for these pieces of equipment are generously raised by third party fundraisers and donors. In addition, some clients' private insurance companies will help pay for new equipment, or will help cost-share with the client or with the Society. We also accept appropriate equipment donations and can provide tax receipts for the estimated value. For more information on our provincial equipment program please contact Lauren at lauren@alsab.ca or (403)228-3857 ext 104.



Alberta Leaders Receive National Awards

On May 3, 2008, ALS Canada held their annual awards event. These awards are presented to outstanding leaders from across the country. Out of 5 categories of recognition, three awards were presented to outstanding leaders from Alberta.

Mary Pollock Walk Award for Outstanding Walk Contributions - Greg, Beth and Vince LeBlanc

This award was presented to the LeBlanc family from Red Deer. Mark LeBlanc battled ALS for 5 years and passed away peacefully in 2006. His brother and parents have been running the Walk for ALS in Red Deer ever since. The LeBlanc's, with the help of their committee, have increased the number of walkers and the amount raised exponentially. They have managed to double the profits from 2006 raising over \$100,000 in 2007 and breaking the goal of \$110,000 for 2008. Their dedication, support and gentle nature makes them truly remarkable people.

Exceptional Fundraising Award Third Party – Charitee Golf for ALS Committee (Gerry Stotts and Dan Huras)

The Charitee Golf Tournament for ALS is an annual event that has raised in excess of \$800,000 for ALS research and equipment in Alberta. The first tournament was held in 1998 in honour of Evelyn Bell, who was living with ALS. The tournament could not succeed without the dedication and commitment of the volunteers that give so much of their valuable time to raise funds and create awareness.

William Fraser Leadership Award For Outstanding Leadership in the Society– Cathy Martin

In 2003, Cathy started volunteering with the ALS Society of Alberta with the Walk for ALS in Edmonton. She then stepped up to chair the committee and built a solid foundation for the Edmonton Walk. Cathy has been a member of the Board of Directors of the ALS Society of Alberta for 5 years and is now the Chair. Her leadership has created a strong foundation to lead the Society into the future that will ensure people living with and affected by ALS will be exceptionally supported.

Upcoming Support Groups and Open Houses

Calgary - ALS Support Group

Support groups are held at the ALS Society office at 400, 320 - 23 Avenue SW from 1:30 to 3 p.m.

Future dates: Sept 13, Oct 4, Nov 8, Dec 6

These groups are co facilitated by Megan Blomfield and Jane Rivest.

Calgary - PLS Support Group

Support Groups are held at the Renaissance at North Hill Mall from 1:00 - 3 p.m.

Future Date: Sept 16

Calgary - ALS Spousal Exceptional Caregiver Group

Spouses of people living with ALS will be notified as soon as dates are selected.

Red Deer

Support groups are held at the MS Society office at 105, 4807 - 50 Avenue from 1:30 - 3 p.m.

Future Date: November 15

Groups facilitated by Jane Rivest.

The Red Deer ALS group and the Calgary ALS Group are general support groups for people living with ALS, their families, caregivers and friends. The PLS group is for people living PLS, their families, caregivers and friends. In all groups there will be much time for general discussion.

For information on all groups, please contact Jane at 1-888-309-1111 or jane@alsab.ca.

Edmonton - Fall Open House Schedule

This monthly opportunity invites persons with ALS, families and caregivers to get together informally - all are welcome! 1:30pm - 3:30pm at the North Region Office #410, 11456 Jasper Ave

Future Dates: Sept 16, Oct 21, Nov 18

Light refreshments provided. Please register by calling (780)487-0754 or 1-866-447-0754

Condolences

Our sincerest condolences go out to the families of the following people who recently passed away:
(March 19, 2008 to August 22, 2008)

Harry Adams
May Albrecht
Harvey Bateman
Dwayne Brown
Traci Dunlop
Debbie Farren
Gerald (Gerry) Fillian
Jean Jelasco

Mark Gerrish
Olga Hilmarsen
Fred Hofstede
Victor Hopfner
Robert Jamha
Wytze Koldyk
Ron Minion
Richard Ostapovitch

Eleanor Reddecliff
Jean Smith
Verna Thoman
Carol Wright
Charlotte Zapisocki
Dario Zgrablic

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.

HELPFUL HINTS

Energy conservation for upper limb involvement:

always recommended, particularly for eating and for personal care.

Light weight utensils such as cups, tumblers, cutlery with adapted handles and non-slip plates and personal care items are recommended. Keyholders, electric toothbrushes with a wider handle, dressing aids such as zipper pulls and button hooks can make life easier. Most items are available from Home Health and Rehab Stores. Your Occupational Therapist (OT) or Speech Language Pathologist (SLP) can advise. Some items may be available from the ALS Society.

Bathroom independence for upper limb involvement:

Have you considered installing a modern Bidet? ToTo or Lubidets are available and provide a warm water wash, warm air dry, with a slowly closing seat lid. Installation by a plumber is required. For further information visit www.knovelty.com or google 'bidets'. Specifications about existing fixtures explained on the web-sites.

Remember that raised toilet seats IMPAIR bidet function so you may need to raise the toilet bowl from below, using a Toilevator, which can be provided by Alberta Aids to Daily Living. Your OT can help you consider this option.

Difficulty chopping and preparing food?

Adapted utensils are available, and being seated is recommended. Also available: Meals on Wheels, pre-packaged frozen meals, and grocery stores that deliver. Check with your local grocery store.

Do you have private Insurance coverage?

It's time to dig out your explanatory booklet and learn what is covered, from power equipment (sometimes called 'durable equipment') to any nursing services. Your OT and Society staff can help explain how this may work in conjunction with publicly funded programs (AADL) and the ALS Society Loan Cupboard.

Financial Aid -Alberta RAMP Program

Allowable Income levels raised July 1st to \$46,500 for couples and \$36,900 for singles. Contact Dennis Spilak at (780)422-8241. Ask for the RAMP Program.

TIP – if your income was higher on your 2007 Tax return, and you have undergone financial changes since then, ensure you adequately describe the changes on your application. Up to \$5000 is available and requires pre-approval.

Helpful Hints

Cheque writing:

Consider using a signature stamp made by a local rubber stamp company. This preserves independent and private financial management if writing is a problem. Remember to visit your bank for approval.

Holiday Equipment needs?

If vacationing in USA or UK, e-mail the national or area ALS or MND organizations to enquire about availability of loaner equipment. Some charges may apply. The ALS Society of Alberta can provide contact information for sister organizations. Advance planning for airlines and hotels is recommended. Most modern power chairs can be transported and your airline's Special Services desk will provide specific information on request.

An Alberta Vacation perhaps?

A local year round recreation spot –accessible and affordable:

William Watson Lodge in Peter Lougheed Provincial Park, Kananaskis.

Lovely rooms, fireplaces, accessible trails in a natural environment.

Call (403)591-7227.

ALS staff have heard wonderful anecdotes of this beauty spot.

Personal Contact Emergency Service:

The Personal Contact Emergency Service is a free community service that allows emergency response professionals to obtain vital contact information. For more information or to register call: 1-866-635-8885

Junk Mail a nuisance?

Visit www.reddotcampaign.ca to rid your mailbox of unaddressed ad mail.

To remove your name from personalized marketing materials, including mail, telephone and fax, or visit www.the-cma.org.

Power Pudding

Eating foods high in fiber and increasing fluid intake helps avoid problems with constipation caused by immobility or decreasing ability to bear down. The recipe below is high in fiber and requires increased fluid intake. Contact your home care nurse if you are having problems, and to avoid a major problem!

Mix together:

1 ½ cups pitted prunes

1 cup unsweetened applesauce

½ cup All-Bran

¾ cup prune juice

Put in blender. Blend well. Refrigerate. Use 1/4 cup daily orally, followed by glass of water.

No SLS for ALS

Sandy Gill, RDH.

ALS Toothpaste Considerations

When providing mouth care for patients with:

swallowing difficulties
feeding problems
inability to spit out
dry mouth



Use a non-foaming toothpaste

A non-foaming toothpaste that does not contain sodium lauryl sulfate is recommended.

The sodium lauryl sulfate (SLS) is the detergent/surfactant and causes foaming of the toothpaste. It increases dry mouth and may also increase the risk of mouth sores for some people. Sodium lauryl sulfate should not be swallowed.

Recommended toothpaste products:

- Biotene dry mouth toothpaste is available at most drug stores.
- New Co. Natural Technology (Calgary-based company) and other brands of toothpaste without sodium lauryl sulfate may be available at your local health food store. Be sure to read the label to ensure that there is no SLS.
- Check the web for these toothpastes available online.

Not able to find the non-foaming toothpaste?

A non-alcohol, antibacterial mouth rinse with fluoride or xylitol added could also be used instead of toothpaste for brushing the teeth and gums.

The alcohol can dry out the tissues inside the mouth. Lack of saliva and a dry mouth can cause an increase in cavities especially along the gumline and root surfaces. The fluoride or xylitol added to these mouth rinses may reduce cavities.

Recommended mouth rinse products:

- Biotene mouthwash
- Oral B Fluorinse

Visit your dentist or dental hygienist regularly for care and advice.

READ the LABEL and No SLS for ALS

More to come on Suction Toothbrushes, Lip and Mouth Moisturizers, Dry Mouth and other helpful dental health tips
Any questions or suggestions for future oral health topics?

Children's Resources:

<http://www.als.ca/allforkids/>

1. Als411 website has been developed by ALS Canada for children, in English and French.
2. As ALS has a fairly low prevalence, children whose parent has ALS are less likely to know peers in the same situation. The website features a large range of resources dealing with issues from how to cope with feelings and emotions, to true stories and testimonials from children who survived the loss of a parent from ALS.

It includes a section for parents providing suggestions on how to talk to children.

Available Books:

- A Parental Guide – Helping Children Cope
- A Booklet for Teens – When Your Parent has ALS
- A Booklet for Children – When Someone Special has ALS



Some Reading - ALS Stories

(available from the Society)

Laugh, I thought I'd Die – Dennis Kaye

Walking Through the Valley: Dealing with the Prospect of Death with Bulbar ALS - Howard C. Lund

Learning to Fall: The Blessings of an Imperfect Life - Phillip Simmons

Cries of the Silent: My Journey with ALS - Evelyn Bell

Behold, I Stand at the Door and Knock - S.C. Biela

Waking Up: Climbing Through the Darkness - Terry L. Wise

Emotional Warfare - Patricia J. Hanna

For Words: A Journal of Hope and Healing - Chris Vais

For Caregivers:

Share the Care - Cappy Capossela

A Caregiver's Guide: A Handbook About End of Life

Care: Family Hospice Care - Harry von Bommel

The Magic of Humor in Caregiving - James R. Sherman

For Children:

Grandpa, What is ALS? - Bonny Gold-Babins

Someone You Know Has ALS - Lois Clark

When Your Parent Has ALS: A Booklet for Teens

When Someone Special has ALS: A Booklet for Children

Helping Children Cope with ALS – A Parent's Guide



Videos:

Making Hard Decisions: The Essence of Being Human

Living with ALS: Mobility, Activities of Daily Living and Home Adaptation

Living with ALS: Communication Solutions and Symptom Management

Living with ALS: Clinical Care Management Discussion among ALS Experts

Nutritional Lifeline: The Feeding Tube Discussion

Barrier Free Housing

Bearing Witness

The Man Who Learned to Fall

Other resources:

Classic Caregivers Ltd:

Opened October 2007. Services provided include: personal care, companionship, home support, and 24 hour live-in to hourly care. Contact Kimberly Hudson at (780)428-2750 in Edmonton and (403)242-2750 in Calgary. This is now one of many agencies listed in the Yellow Pages under Home Health Care Services. A useful resource if you are considering or eligible for Self Managed Care.

Community Rehabilitation Interdisciplinary Service (CRIS)

Helps those with complex rehabilitation needs remain independent in the community. CRIS provides occupational, physical and speech therapy. Programs in Calgary and Edmonton. For info call: (780)735-2413 or your Home Care Coordinator or ALS Clinic Coordinator.