



NEWSFLASH

A publication of the ALS Society of Alberta; 400, 320-23 Avenue SW, Calgary, AB T2S 0J2
North Region Office: 410, 11456 Jasper Avenue, Edmonton, AB T5K 0M1 Tel: 780-487-0754;
Toll Free: 1-866-447-0754; Fax: 780-486-3604; Provincial Toll Free: 1-888-309-1111; Website: www.alsab.ca;

April 2005

FUNDRAISING EVENTS FOR SPRING/SUMMER 2005

Betty's Run for ALS – Calgary - June 12

North Glenmore Park- Calgary (\$ 30 Entry Fee)
Registration 9:00 AM; Start: 10:00 AM
Contact: ALS Hotline 403-260-2022

Walk for ALS – Cold Lake – June 11

Lakeland Lutheran Church – across from Millennium Trail (no entry fee)
Registration: 9:00 AM; Start: 10:00 AM
Contact: Michelle Feduniak – 780-639-2360

Walk for ALS – County of Mountain View – June 11

Didsbury Train Station (no entry fee)
Register: 9:00 AM; Start: 10:00 AM
Contact: Wayne Steer – 403-228-3857

Walk for ALS – Edmonton – June 11

William Hawrelak Park (no entry fee)
Registration: 9:00 AM; Start: 10:00 AM
Contact: Phyllis Javorsky – 780-487-0754

Walk for ALS – Lethbridge – June 11

Fort Whoop-Up (no entry fee)
Registration: 10:00 AM; Start: 11:00 AM
Contact: Lorin Shockley – 403-328-7590

Walk for ALS – Lloydminster – June 12

Bud Miller Park (no entry fee)
Registration: 10:00AM; Start: 11:00 AM
Contact: Marie Perkins – 780-875-8241

Walk for ALS – Medicine Hat – June 11

Heritage Pavillion, Strathcona Island Park (no entry fee)
Registration: 9:00 AM; Start 10:00 AM
Contact: Michelle Compton – 403-504-0071

Walk for ALS – Red Deer – June 11

Kiwanis Picnic Shelter – Little Chief Park (no entry fee)
Registration: 9:00 AM; Start: 10:00 AM
Contact: Phillis Edwards – 403-227-5157

Walk for ALS – Rocky Mountain House – June 18

Crimson Lake Provincial Park (no entry fee)
Registration: 9:00 AM; Start: 10:00 AM
Contact: Terry Layden – 403-845-2968

Corporate Calgary Charity Society Charitee Golf Tournament – June 20

Pinebrook Golf & Country Club (\$2,500. team entry fee)
Contact Len Esler – 403-282-4640

Content of the Spring Newsletter

This newsletter, like the other versions of the *NewsFlash*, is packed with information designed to help people living with ALS. Some of the information in this issue may seem a little dark or even paradoxical as this publication appears at a time of new life and rebirth – Spring – yet covers some issues that are seldom discussed dealing with end of life issues. This particular topic is seasonally more akin to Winter.

Chris Mann, a long time ALS advocate and person living with ALS, addresses some of these end-of-journey issues and has framed them from a perspective of one person living with ALS.

Throughout Chris' fight against ALS he has often faced the fears and challenges that many of us dare not. Through his courage and insight, I hope that this article inspires others to investigate some important questions so as to bring new appreciation of life issues, irrespective of where they lie on the continuum of the circle of life.

Wayne Steer, Editor

Over the past 3 years, Chris Mann has participated in the 2003 ALS National Public Service Announcement along with Wendy Crewson, and was the 2003 Betty's Run for ALS Ambassador. Chris has spoken to neurologists, chaplains, OT and nursing students as well as the ALS team to keep us all on our toes as to what we need to learn from him and others with ALS.

Many times, Chris has chatted with people and families living with ALS to help them look at things in a different light.

Chris has submitted an article that touches on the importance of the palliative care team as an integral part of the ALS team. He is also planting a seed for those who may need it, to be open and accepting of the palliative care team when the time comes.

Helpful Hints

- * **Electric toothbrush** - easier to manipulate than a regular toothbrush
- * **Satin sheets** (or sheets made with polyester wedding gown fabric) can make it easier to move around in bed.
- * **Mittens to use with power chairs** - make with fleece fabric, no thumbs, but cut a hole in the middle of the palm so your hand can then fit over the joy stick.

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.

Letter of One Man's Experience with ALS

L.D.W.D. (Let Die with Dignity) *By Chris Mann diagnosed August 2001*

I have been assisting to educate the public about ALS since shortly after my diagnosis. Just as importantly, I have also been part of a collaborative group to inform diagnosticians and PALS* that we can and must learn to live with ALS. My dedication to both preceding principles has remained unchanged. The extent to which ALS has affected me has changed drastically.

One day as I lay on my bed resting, my mind locked onto the most recent factor of my life. I was unable to move. Could be kissed but could not kiss; could be hugged but could neither hug nor scratch an itch, wipe perspiration from my eyes or move my head to get the BiPap mask more comfortable. All I was able to do was stare at the ceiling. A major depression descended over me. Whenever I laid down the fog came back; I would start to cry uncontrollably. The depression lasted for more than a week and was finally brought to the attention of our ALS Society coordinator by my wife. Jane Rivest told me I still had options. She put me in touch with my palliative care nurse. In my mind I had completely lost control over my dignity.

My nurse explained that I was still in control and had in fact already made some decisions, which could impact my remaining life, in regards to which medical conditions I choose to treat. She is professional, informed and humanistic. She spoke of options, corrected some problems with my medications and then set up a meeting with my full palliative team. My depression was lifting. The decisions about medical procedures I had made in the past were indicative of exercising control - these options still remain today. The palliative care team is in place to remind and reconfirm options. Their function is to ensure you're not in trauma or pain. They will assist you in writing your Living Will and ensure that you are aware of the implications of each decision. They are in no way willing or able to assist you in suicide. They say that I have stated my religious beliefs, which don't allow for suicide. We are on the same page, as neither do their moral and legal requirements. Before ALS, what "let die with dignity" meant to my wife and me was that you must always wear clean underwear in case of an accident. Now, living with ALS, does this mean I have to get dressed in a suit every morning?

No, I was informed it was about maintaining your human dignity. This was very important to me as I thought I had lost all dignity. When you can't do



Chris Mann pictured in 2003 with Wendy Crewson, Canadian Gemini Award Winning Actress & Patron of Betty's Run for ALS

anything by yourself, I thought dignity was a thing of the past. At least I would be able to die according to my wishes.

It is not my purpose to be defeatist nor moribund; however, coming to this point sucks. You may not need to consider what I am discussing but it has been my experience that when PALS talk, death is never mentioned. Even though it may be very necessary for some, myself included. Chris can be reached at <http://ranger03.com/ALS.html>

*PALS (person living with ALS) a term that is often used by people living with ALS, but not used by ALS Canada.

Palliative Care Resources

For more information on Palliative Care and the resources available to you, please contact the ALS Society of Alberta toll free at (888) 309-1111 or Alberta North Region toll free at (866) 447-0754.

Advocacy Committee

The Advocacy Committee has two main projects underway. The first is a Physician's Awareness Campaign, aimed at providing Alberta doctors up to date information on ALS. The second project is Phase 2 of our Advocacy Survey. Your comments on this survey will guide our advocacy efforts for the next couple of years. Please be sure to complete your copy of the survey. If you would like to receive a copy of this survey, please call Phyllis at 780-487-0754

RESOURCE DEVELOPMENT



Edmonton Walk for ALS 2005

Mark June 11th on your calendar and be prepared to have fun at Hawrelak Park. This year's walk will start at 10:00 AM with registration starting at 9:00.

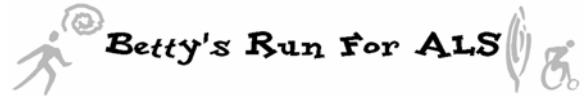
We have already lined up the energizing sounds of the C-Jam Big Band, enlisted a Piper to lead us on the right path, and will have inspiring speakers to lift our hearts as we walk around the park.

The Team Captain Kits, pledge forms and registration forms are now available. Please call Phyllis @ 487-0754 to arrange to pick up your forms. If you have any questions about the walk, wish to be a team captain, or wish to volunteer for the walk, please call Cathy at 463-4905 or email cathy@alsab.ca or phyllis@alsab.ca. With your involvement, we are looking forward to making this walk the best one yet!

VOLUNTEERS NEEDED FOR:

Registration table/incentives, water, traffic control, display booth, greeters, set up/tear down, signage and miscellaneous tasks

Please contact Phyllis at 487-0754 or e-mail at phyllis@alsab.ca to sign up.



A Brief History

In August 1996, Betty Norman, a vivacious, fun-loving, and very caring lady was diagnosed with ALS. Betty, her family and friends were frustrated by the lack of awareness about ALS and the small amount of research underway at that time. In June 1997, 2 short weeks before Betty passed away, the first walk/run in Betty's honour was held in Calgary to raise money for ALS and to help increase awareness.

In June 2004, Betty's Run for ALS reached the extraordinary milestone of raising in excess of \$1,225,000 in its eight year history! To date over \$500,000 has been sent to ALS Canada to help fund research and to help find a cure. The remainder has stayed in Alberta to help provide appropriate equipment and support for people living with ALS now.

What drives us to do this year after year? Each and every member of the committee has had a friend or family member with ALS. We continue helping the ALS Society of Alberta "make every day the best possible day for people with ALS."

For info on Betty's Run for ALS contact the Hotline at 403-260-2022 or e-mail wayne@alsab.ca.

Coming SOON – Personalized fundraising websites available through www.alsab.ca/events website. Look for it in Mid April 2005!!!



Hike for ALS

This fundraiser appeals to hikers and outdoor enthusiasts. The ALS Society of Alberta in partnership with the ALS Society of Canada is developing a fall fundraiser centered on one or two pristine hikes within Alberta. If you have interest in assisting with this project, please contact Wayne at 888-309-1111 or visit us at www.alsab.ca/events for more details.

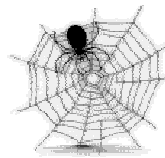


To Register on-line for the various **Walks for ALS** throughout Alberta please go to www.als.ca/events



Acres for ALS: Harvest of Hope

This grassroots fundraiser for rural Alberta, Saskatchewan and Manitoba is currently in the planning stages. If you have agricultural/rural connections or experience, your assistance would be very much appreciated. To see how you can participate please call Wayne Steer at 888-309-1111 or e-mail at wayne@alsab.ca.



Be sure and visit our new and improved website coming by mid April at: www.alsab.ca



Corporate Calgary Charity Society Annual Charitee Golf Tournament

This Annual Golf Tournament will again be held at Pinebrook Golf & Country Club on June 20, 2005.

For more information on this event and to become involved in raising a little green for ALS on the green, contact Len Esler at 403-282-4640.

SPECIAL HEARTFELT THANKS!

To all who have made Donations of Time, Money, Energy & Love to the ALS Society. We do so MUCH more because of YOU!

"Together, we do make a difference"

DONATIONS



On January 30, 2005 **Rhonda Withnell and Don Bradshaw** performed "Once Was" CD Release Concert at the Varscona Theatre in Edmonton. The proceeds were donated to The ALS Society of Alberta. Thank you Rhonda for your support.



Geoff Badger of **First Associates Investments Inc.** presenting a cheque to Patricia Ordyne and Cathy Martin on March 7th, 2005. Thank you Geoff.

**Considering Estate Planning?
Wondering how to make a
difference to society and
minimize estate taxes?**



Join us at the 2005 Legacy Seminar Series on May 17th & 18th, 2005 in Calgary at the Red & White Club, 1833 Crowchild Trail N.W.

Topics include Wills, Estates Planning, Strategic Tax Planning and End-of-life Issues.

Admission is **FREE** but seats are limited. Reserve yours now by calling Wayne Steer toll free at 888-309-1111 or by e-mail at wayne@alsab.ca For more information visit us at www.alsab.ca/contributors

Volunteer Inquiries

For anyone wishing to find out more about volunteer opportunities with the ALS Society of Alberta, please contact:

Throughout Alberta:

Wayne at (403) 228-3857

Toll Free 1-888-309-1111

E-mail: wayne@alsab.ca

North Region:

Phyllis at (780) 487-0754

Toll Free 1-866-447-0754

E-mail: phyllis@alsab.ca

Message From The Executive Director ALS Society Of Alberta

I have cornflowers growing in my garden. Well, at least they will be coming up soon, and as well as looking bright and cheerful, they remind me to stop a moment, to remember those living with ALS and the many lessons I have learned from those who are no longer with us. I have learned to take joy and pleasure in sunrises and simple flowers, in friends, family and folk I meet along the way and in the memories and echoes of shared laughter.

I have a garden, rather than just a yard, because one day many years ago, Lois Hole took the time to "turn me on" to gardening. This year, as I enjoy the colours and the smells and yes, even the work, I will remember Lois. As the Lieutenant Governor, The Honorable Lois E Hole was Patron of the ALS Society of Alberta. Her warmth and compassionate caring nature supported and encouraged all of us and the ALS Society of Alberta is truly honored to have been associated with her.

So as you pin on your cornflower, remember not just those affected by ALS, but also all those who give of themselves, each in their own unique way, to help us "...make everyday the best possible day for people with ALS..."

Together, we do make a difference.
Mary Hatcher, Executive Director
ALS Society of Alberta



The Cornflower is the National symbol of ALS

Our Sincere Condolences to the Families of:

Heather Layden	Michael Coggins
Raymond Peterson	Terry Schultz
Doug Evans	Akil Khouri
Paul Beland	Richard Parker
Keith Schneider	James Read
Jeanne Massel	

The ALS Society of Alberta respects privacy and adheres to all legislative requirements with respect to protection of privacy. The ALS Society does not rent, sell or trade contact lists. Personal information is used only to delivery services, inform you of Society activities including programs, services and special events, funding needs, volunteers & donor opportunities. If you wish to be removed from any ALS Society contact list please contact your nearest Society office.

NORTH REGION NEWS

Education Sessions at ALS Society N Region Office

Space is limited, so please register at 487-0754
Parking: West side of Shoppers Drug Mart and meters on adjacent streets

WEDNESDAY, APRIL 27TH, 2-4 PM.

Rosabelle Dougela – Finding Joy in Living Amidst Adversity

Revealing the secrets of Joy in Living for care-giver and recipient, this session provides the principle and practical guidelines necessary to develop joyful living. Rosabelle is a retired teacher and business owner, and is the author of Finding Joy in Living.

WEDNESDAY, MAY 18TH, 4-6 P.M.

Dr. Ming Chan, MD FRCP – Physical & rehabilitation measures to improve symptoms and function for people living with ALS

Functional decline can be a direct consequence of ALS or can arise from unrelated causes. A common difficulty is musculoskeletal pain and limited joint movement. This session outlines treatment and strategies to improve symptoms and capacity for people living with ALS.

THURSDAY, JUNE 30TH, 1:30-3:30 P.M.

Dr. Sanjay Kalra – Research Update: Why Don't We Have a Cure Yet?

This session reviews: our understanding of what ALS is and what causes it; explains the hurdles present that make it difficult to find a cure and presents an overview of recent drug studies.

Capital Health Authority Community Rehabilitation Program Edmonton General Hospital Continuing Care Centre Phone: 780-482-8163

For Adults with Neurological conditions who live in the community and require rehabilitation for:

- Mobility, movement, or physical strength
- Independence in doing day-to-day activities such as taking care of personal needs
- Talking and comprehending what other people say.

Adults must require **two or more** rehab services to utilize this program: physiotherapy /occupational speech or respiratory therapies.

ALS Clinics

ALS Clinic – Edmonton (Pat Carey) 780-407-3718
Research Coordinator 780-407-3719
ALS Clinic – Calgary (Janice Hagel) 403-944-4323

Pilgrims Hospice

Living with a life-threatening illness is often difficult without additional support and care. Pilgrims Hospice is an organization that can be of great assistance to ALS patients and their families.

Pilgrims Hospice operates the **Adult Respite Day Program** on weekdays. The program offers professional nursing care, volunteer companionship, recreational activities, medication supervision, a hot lunch and refreshments throughout the day. All of the necessary assistance is provided as it is required.

People attending Hospice enjoy companionship and social activities in a compassionate, safe and homelike atmosphere. They interact with others and are treated with dignity, respect; an opportunity to live each day as normally as possible.

There are opportunities to participate in a variety of activities such as board games, cards, or movies, and unstructured time for music, reading, conversation, journaling or personal reflection.

Home Hospice adds to the care provided by health professionals. The presence of volunteers can improve quality of life for those who are ill and those who care for them. Services provided are agreed upon by you, your family and the Home Hospice Coordinator. Pilgrims Hospice tries to be flexible to meet your needs. Care in the home enables those faced with life-threatening illness the opportunity to stay at home as long as possible and to die in a familiar environment if that is their wish.

Call 413-9801 or visit Pilgrims' website:

www.pilgrimshospice.ca for more information. You can also send an email to the Care Manager (TracyD@pilgrimshospice.ca) or the Home Hospice Coordinator (AmyM@pilgrimshospice.ca)

CAREGIVERS CORNER

Attention Caregivers

Alberta Caregivers Association

14220 – 109 Avenue, Edmonton, Alberta T5N 4B3
Tel: 780-447-9224 Fax: 780-488-3561
Website: www.AlbertaCaregiversAssociation.org
E-mail: admin@AlbertaCaregiversAssociation.org

Family Caregiver Centre

1509 Centre Street South, Calgary, Alberta T2G 2E6
Tel: 403-303-6027 Fax: 403-263-9063
Website: www.familycaregivers.ab.ca
E-mail: family_caregivercentre@calgaryhealthregion.ca

South & Central Alberta

Central & Southern Alberta Supports

Red Deer Support Group:

When: Saturday, June 25 (1:30 to 3:00 p.m.)
Where: MS Society office at 4322 – 52 Avenue
Co-facilitators: Patricia Ordynec, Jane Rivest
Guest Facilitator: James Strachan, former chaplain at the ALS Clinic in Calgary

Calgary Support Groups:

Saturday Support

Participants: These groups are intended for people living with ALS, their families, friends and caregivers.
When: Saturday April 9 & May 7 (1:30 to 3:00 p.m.)
Where: ALS Society office @ 400, 320 – 23 Ave. SW.
Co-facilitators: Jane Rivest, Client Services Coordinator and Laura Cavicchi, formerly the social worker at the ALS Clinic

Tuesday night support

Participants: These groups are intended for people who have lost friends and family members to ALS.
When: Tuesday April 26th & May 24th from 7:00 to 8:30 pm
Where: St. Anthony's Catholic Church, Parish Hall, 5340 – 4 Street SW.

Any questions? Please call Jane at 1-403-714-8211

Hospice Calgary Society

Hospice Calgary Society offers professional child and youth counseling, parent support and education, and community consultation in the area of death and dying.
 Contact:

Hospice Calgary Society
 Suite 900, 833 – 4th Avenue SW
 Calgary, AB T2P 3T5
 Tel. and Fax: 403-263-4525
 E-Mail: info@hospicecalgary.com

ALBERTA SUPPORTS & INFORMATION

Canadian Abilities Foundation

On Line Workshops – Free for Writers with Disabilities – If you love expressing yourself in writing and dream of seeing your name in print, this workshop is for you! Find out how to write effectively, promote yourself to editors and make a difference in your community using the written word. Contact: able@abilities.ca or call 1-888-700-4476 (ext. 232) to register.

Supporting the ALS Society When You Shop On-Line

Make your shopping easier and support the ALS Society of Canada. When you shop on-line through a fully secure web site a percentage of your purchases is contributed to the non-profit group of your choice at no extra cost.

Here is what you do in 3 easy steps:

- Step 1: Connect to either www.GoodDeedShopping.com or www.cangive.ca
 Step 2: Select a group to support.
 Step 3: Select an on-line e-tailer and go shopping

Traveling?

Discover the Disability Travel Card

Easter Seals/March of Dimes National Council is proud to celebrate its 26th year of making travel more accessible to Canadians with physical disabilities.

The Disability Travel Card provides identification for an accompanying adult attendant to travel at no cost with a person with a permanent disability.

For more information or to obtain an application, contact in Alberta (403) 235-5662 or by Fax: (403) 248-1716 or by visiting www.esmod.ab.ca

EQUIPMENT POOL NEWS

Equipment News:

ChatterVox Voice Amplifier



Recent Addition to ALS Society Loan Cupboard

- Suited to quiet and clear speech.
- A portable voice amplification system elevates vocal output of people with neurological or functional voice disorders. Amplifies voice 12-18 db.
- Worn as a fanny pack around the waist, lightweight (1lb.6oz) and comfortable.
- Features high capacity Nickel Metal-Hydrate (NiMH) rechargeable power system, can provide up to 14 hours of continuous use. Recharging can be completed in 5 hours or overnight.
- DynaMic Headset microphone.

In **South Region** contact: Lyn Skipper, Equipment Program Coordinator on 1-888-309-1111 or 403-228-3857, email: lyn@alsab.ca

In **North Region** contact: Sue Decker SLP, at 780-487-0754, or 1-866-447-0754.