



# NEWSFLASH

A publication of the ALS Society of Alberta - N. Region, 410 - 11456 Jasper Ave., Edmonton, AB T5K 0M1

May, 2004

## ADVOCACY DAY AT THE LEGISLATURE!



Training Day, April 25th.

On April 26, forty-five excited people including those living with ALS, volunteers, Board members and staff descended, in an orderly and dignified fashion, on the Alberta Legislature. Throughout the day small groups met with 49 MLAs, sharing the message "Thus **Albertans living with ALS** respectfully **invite the Government of Alberta** to provide **leadership in collaboration** to **develop and deliver equitable access** to support of **wellness and activities of daily living** for all **Albertans living with ALS.**" The message was delivered with passion and personal stories, putting together real faces along with the facts.

This day was the culmination of a full year's work of learning, planning and organizing. We greatly appreciated the leadership and guidance provided by ALS Canada and the direct involvement by Susan Graham Walker and Paul Davidson. The Alberta volunteer energy and focus came from Laura Kemp-Hanson and ALS AB Board members Cathy Martin and Mike Klein. They spearheaded the committee that included N AB staff Patricia Ordynec and Karen Andrus. We also owe a sincere vote of thanks to organizer extraordinaire Cathy Neale. ***Together, we do make a difference!***



Relaxing back at the Inn on 7th after meetings.

*Mary Hatcher, Executive Director*



## Edmonton Walk to D'Feet ALS 2004



**Mark your calendars now!**

### Edmonton Walk to D'Feet ALS 2004

**When:** Saturday September 25th

**Where:** Hawrelak Park

**Time:** Registration at 9:00 AM  
Walk at 10:00 AM



### DID YOU KNOW ....

That participants in Walk to D'Feet who write letters (sent by mail or email) raise nearly 4 times as much money than those who don't? Across Canada the average walker raises about \$150. Those who wrote letters to their friends, family, neighbours and/or coworkers about why they were walking in the Walk to D'Feet ALS raised an average of \$500 per person.

Tell your story about how ALS has affected you or someone you love. Some of the people you write to will support you with money and maybe some will even come out and join you for the walk with sponsors of their own!

If you would like more information about sending letters and what to say visit [www.alsab.ca](http://www.alsab.ca) or call the office and we will send you samples. The ALS Society will photocopy your letters and send them out for you. All you have to do is write and sign an original, supply addressed envelopes and drop them off or send them to the ALS Society office and we will do the rest. Call 487-0754 to arrange.

Now is the time to get started. Help us to raise awareness and money to 'help make each day the best possible for people with ALS'.

*"Together we do make a difference."*



ALS Society of Alberta

### Edmonton Walk to D'Feet ALS 2004

#### Kick off Lunch

**When:** June 23rd

**Time:** Noon - 1:00PM

**Where:** Society for the Retired and Semi-Retired  
15 Sir Winston Churchill Square 102A Avenue and 100 St.

Everyone is welcome to come and find out about this year's plans and how to be involved as a Volunteer, Team Captain or Walker.

Please RSVP - 487-0754



Details for other walks around the province are being confirmed and we will keep you posted as details become available.

## COMING EVENTS

**Betty's Run for ALS- Sunday June 13th**, North Glenmore Park, Calgary For further information call 403-260-2022 or visit [www.alsab.ca](http://www.alsab.ca) Online registration [www.runningroom.com](http://www.runningroom.com)

**June is ALS Awareness Month.** The cornflower is the emblem of ALS because despite it's fragile appearance it is a hardy wildflower found throughout Canada. Like the cornflower, people with ALS show remarkable strength in coping with a devastating disease. Like the cornflower, awareness of ALS and funding for care and a cure is growing across Canada.

**Cornflower Day - Saturday, June 12th, Lloydminster.** Volunteers are needed to make cornflowers available in the Lloydminster Mall. If you live in the Lloydminster area and could help for an hour or 2 please call Marie at 780-875-8241.

**Cornflower Day - Saturday, June 19th, Edmonton.** Volunteers are needed to make cornflowers available at Edmonton area Bay stores. Morning and afternoon volunteers time slots. If you can help please call Karen 487-0754 or email [karen@alsab.ca](mailto:karen@alsab.ca).

### 4th Annual WALK TO D'FEET ALS

**Edmonton -Team Captains Needed - Saturday, September 25th**  
Mark your calendars now! Last year's walk raised \$85,000 and we can do better this year. Planning is underway so if you have any great ideas about how we can make the walk bigger and better or would like to help please call the office.

**Volunteers Needed** - Do you live in a small community? Volunteers are needed to help spread Walk to D'Feet across the province. Walks can happen in any size community. Walks can be big or small and they all help to raise awareness and money to aid in provision of services and research into cause and cure.

Why not have a walk in your community and invite your friends and neighbours to join you?

For more information please call Brenda 1-866-309-1111 or email [brenda@alsab.ca](mailto:brenda@alsab.ca)

## SERVICES

- Need to thicken fluids? A variety of thickeners are available for delivery throughout Alberta.  
Central Care Medical Pharmacy  
Aldritt Bldg., W. Tower 14310-111 Ave., Edmonton  
Phone 780-451-9510 Fax: 780-451-0897 or  
Email: [pharmacy@centralcarepharmacy.com](mailto:pharmacy@centralcarepharmacy.com)
- Does anyone know of a ladies hair dresser who 'comes in' to the home? Please share the information through the office (487-0754)
- **The Support Network** offers a variety of services including:  
Community Services Referral Line - 482-4636  
24 hour Distress Line - 482-4357  
No fee Walk In Counseling  
Seniors Abuse Help Line 454-8888

## CAREGIVERS' BILL OF RIGHTS

I have the right:

- To take care of myself. This is not an act of selfishness. It will give me the capability of taking better care of my loved one.
- To seek help from others even though my loved one may object. I recognize the limits of my own endurance and strength.
- To maintain facets of my own life that do not include the person I provide care for, just as I would if he or she were healthy. I know that I do everything I reasonably can for this person and I have the right to do some things just for myself.
- To get angry, be depressed and express other difficult feelings occasionally.
- To reject any attempt by my loved one [either conscious or unconscious] to manipulate me through guilt, anger or depression.
- To receive consideration, affection, forgiveness and acceptance for what I do for my loved one for as long as I offer these qualities in return.
- To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my loved one.
- To protect my individuality and my right to make a life for myself that will sustain me in the time when my loved one no longer needs my full time help.
- To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired older persons in our country, similar strides will be made toward aiding and supporting caregivers.

*Wendy Lustbader*



Liberal Leader Kevin Taft and MLAs Don Massey and Laurie Blakeman during a meeting with members of the ALS Society.



Hon. Gary Mar, Minister of Health and Wellness was one of the 49 MLAs who met with members of the ALS Society on April 26th.



## PERSONAL DIRECTIVES

It is said that everyone who drives, or is over 16 should have a Personal Directive to ensure that the desired care is provided. If a 911 call is made in an emergency, remember that all available interventions will occur **UNLESS** you have stated otherwise on a Personal Directive.

### What is it?

A Personal Directive document allows individuals to make decisions in advance regarding:

- medical intervention and care
- preferred placement, if long term care is required
- who may visit
- what types of activities are enjoyed
- even, preferred foods

The Personal Directives Act became law in Alberta in December 1, 1997. Personal Directives do not involve financial decisions and a lawyer is not required.

Personal Directives allow for the appointment of an 'agent' or 'proxy' who will make decisions on your behalf, should you become incapacitated.

Your family, physicians, neurologist, ALS Clinic and Home Care Coordinator should each be given a copy. See chart below for further clarification. Sample Directives are available from the Society office.

## WHAT IS THE DIFFERENCE

### Personal Directives, Enduring Power of Attorney, Wills :

#### 3 Legislations compared

	Decisions made by YOU in advance	Decisions made for YOU by the court
<b>Financial decisions</b> ( <i>\$ and property</i> )	Enduring power of attorney (EPA) <ul style="list-style-type: none"> <li>• Attorney chosen by you</li> </ul>	Trusteeship <ul style="list-style-type: none"> <li>• Trustee(s)</li> </ul>
<b>Personal Decisions</b>	Personal Directive Act <ul style="list-style-type: none"> <li>• Agent chosen by you</li> <li>• Specific instructions</li> </ul>	Guardianship <ul style="list-style-type: none"> <li>• Guardian(s)</li> </ul>
<b>Decisions after death</b>	Will / Last Testament <ul style="list-style-type: none"> <li>• Executor</li> </ul>	Interstate Succession Act (Generic Will written by province)

**Power of Attorney** (circ 1906) - the moment the document is signed, it is in effect. eg. banking, paying bills, selling items (specified). Power of Attorney ends when a person loses their mental capacity.

**Enduring Power of Attorney** (circ 1906) - This document is used when the person becomes mentally incapacitated. We should all have this document prepared.

**Executor(s)** - is the person assigned to look after the Will. This person cannot make decisions while the person is alive. However, the same person can be listed in the 3 documents.

**Enduring Power of Attorney and Personal Directives** ARE NOT the same document. They cannot be combined. Legislature is re-evaluating this in 2008!

Reference: Inservice by Monique Rigole MSW: AB Seniors-Office of the Public Guardian 297-4628 April 20, 2004

Summarized: Janice Hagel (ALS Clinic- Calgary)



## IN TOUCH

My thanks to those of you who attended the 'In Touch' session in March. Many of you were interested in knowing about communication devices. The following information has been adapted\*.

When speech is no longer meeting important communication needs or when speaking is effortful and tiring, communication is more efficient using alternative means. If you have little or no arm or hand weakness, handwriting is a good way to clarify misunderstandings. Handwriting is the most natural, accessible, and portable means of alternative communication. Handwriting is also more rapid and obviously less expensive than any mechanical or electronic communication device.



Congratulations to Aaron and Marie Perkins pictured here with their daughter Juliana. They were married April 17th.

If your arm and hand muscles are weak so that handwriting is very difficult, hard to read or even impossible, the speech-language pathologist may help you with an augmentative communication approach. Augmentative communication may include boards or books containing pictures and words, electronic devices, or other strategies.

Examples of devices commonly used include portable keyboard devices with and without a voice output and hand held "palm" devices that can be used for communication and other functions. There are also communication software programs that can be used with a computer. Many of these devices have been purchased by the ALS Society and

are available through the office and the I Can Centre at the Glenrose Hospital. Contact the office for further information.

The time may never come when your speech is no longer useful or requires too much effort to use as your only means of communication. However, knowing your physical capabilities and communication needs, the speech-language pathologist will be able to select an appropriate augmentative communication device should you need one.

*Sue Decker, SLP*

\* Yorkston, K.M., Miller, R.M., & Strand, E. A. (1995). Management of Speech and Swallowing in Degenerative Diseases. San Antonio: Communication Skill Builders.

## HELPFUL TIPS

**Avoiding Constipation** (excerpted from Living With ALS)

**Constipation** - can be an uncomfortable symptom in ALS. Causes include decreased mobility, less exercise, decreased fruit, fluid and vegetable intake and a reduced ability to bear down.

**Management** - Review medications to ensure constipation is not due to overuse, increase fluids and discuss bowel management with appropriate health professionals - home care staff and your physician. Stool softeners and laxatives may be required to re-establish and maintain a good routine.

**Power Pudding** can be a helpful recipe. This consists of equal parts of prunes, prune juice, applesauce and bran. Two tablespoons with each meal and at bedtime can be taken as a preventive measure along with increased fluids.

Talk to your physician and home care nurse. With a good bowel maintenance program problems can be avoided!

## FOOD FOR THOUGHT

Hope is like a road in the country; there wasn't ever a road, but when many people walk on it, the road comes into existence.

*Lin Yutang*

## CONDOLENCES

Our sincere condolences to the families of:

Carol Boychuk  
John Brandabura  
Ronald Craig  
Lois Lofstrom  
Dorothy Poppleton  
Alma Rusich  
Dennis Williams

## Bereavement Interagency Support Network Presents GRIEF INFORMATION SESSIONS

Join us on the following Saturday mornings to learn more about the grief journey. Everyone is welcome. No cost. Free Parking.

Time: 10 AM - 11:15 AM

Location: Park Memorial Reception Centre - 11015-101 St.

June 19 - Men Grieving  
July 17 - Surviving Suicide

For more information call:  
Verna Klimack 780-430-1002  
Carol Kodish-Butt 780-454-1231  
Margaret Robinson 780-467-5624

