



February, 2003

NEWSFLASH

ALS Society of Alberta—Edmonton Office

410-11456 Jasper Ave., Edmonton, AB T5K 0M1

Phone: 487-0754 Fax: 486-3604 Toll Free: 1-866-447-0754

Email: Patricia—patricia@alsab.ca or Karen—karen@alsab.ca

2002 YEAR IN REVIEW WITH YOUR HELP WE HAVE:

Relocated – furnished space for \$217.00

**Served 89 individuals and families with ALS
by providing information, support, resources,
76 items of equipment and computers**

Provided 16 In-Services to 415 Health Professionals

Collaboratively worked with the community

Hosted a Remembrance Service – 56 attended

Supported Fund Raisers:

An Evening of the Music of Elton John, We've Got Rhythm,
Cruise for the Cure, Great Human Race, Cornflower Days, Quilt Raffle
2nd Annual WALK to D'FEET ALS - \$102,000

Gratefully Accepted another \$72,000 in donations locally

Developed a regular newsletter 'NewsFlash'

Developed the Volunteer Program
Chapter, Office assistants, Special Events, Walk to D'Feet ALS
Volunteers gave more than 1100 hours to the Society.

**Staff completed courses in Bioethics and HR Management, and
attended 3 conferences on ALS**

THANK YOU

2002 saw relocation and growth in the Edmonton office, and we look forward to 2003 being even better. With your help we will continue to strive toward the goal of 'making each day the best possible' for people with ALS and their families. Thank you to the many who helped in 2002.

How you can help in 2003:

Our Chapter Project Team is in need of new members to help carry on the work of the Society. 'Walk to D'Feet ALS' has grown and needs more volunteers. Also we need a Volunteer Host/ess for upcoming Information Sessions. For further information please call the office.

Holding a fundraiser for the Society is another idea. These can be large or small. As much as we would like, we do not have the manpower to do it all. If you do the organizing we will help by advertising in the newsletter, finding volunteers, sell tickets through the office and provide information and support in any way that we can. Give us a call with your ideas and let's see what can happen.

Donations to the ALS Society are always welcome. These can be made by cheque, Visa, or MasterCard. They can be mailed or phoned to the office. Receipts are issued for all amounts over \$20.00.

"Together we do make a difference."



Sid Vander Meulen, President of Edmonton Realtors Foundation presenting a cheque for \$15,000 to Patricia Ordynec of the ALS Society of Alberta on December 19th. Thank you for helping us to help others.
"Together we do make a difference."

PILGRIMS HOSPICE

Edmonton's only volunteer hospice

Since its inception, several people with ALS have found great joy and peace by attending the Day Program at Pilgrims Hospice.

The Day Program at this volunteer hospice in the west end, continues to assist persons with life threatening illness. The Day Program provides a supportive and loving environment, a variety of activities or chats, wonderful lunch, and a special and meaningful time out. Family caregivers also benefit by having respite, and time to rejuvenate.

Hospice is not just a 'place' - it is a concept of care which aims to improve quality of life, and is an extension of home. It allows people to be cared for to the extent possible by family, while providing needed respite to caregivers. The focus is on life, and care extends to family and friends helping them care for loved ones and care for themselves. Address: 9808 - 148 Street. Edmonton. To arrange a visit call Joanne at: 413-9801.

An additional service will be provided by Pilgrims Hospice in the near future - A Community Visitation Program. Details in future NewsFlash.

WORDS OF INSPIRATION

Never talk defeat. Use words like hope, belief, faith and victory.

Norman Vincent Peale

EDUCATION SESSIONS

FOR SALE

Wednesday February 19th, 2003

Speaker: Sue Decker SLP

Topic: "Speech and Communication—Keeping in Touch"

This session answers questions about speech function and communication and includes info on alternative ways to communicate. An opportunity to share coping mechanisms while dealing with changes in speech ability is provided.

Thursday March 13th, 2003

Speaker: Dr. Wendy Johnston

Topic: "Of Mice and Men" - How to think about advances in research when you or your loved one has ALS.

This session includes some of the findings of the International ALS Conference held in Australia in October 2002, at which Dr. Johnston presented.

Wednesday, April 23rd

Speaker: Bob Mitchell, Office of the Public Guardian

Topic: The differences between Living Wills, Advanced Directives, Power of Attorney, Guardianship/Trusteeship and Personal Directives.

The preparation of a personal directive can be done by any adult Albertan who wishes to plan for their future.

Space is limited so confirm your space by calling the office @ 487-0724.

RECOMMENDED THROUGH THE GRAPEVINE

PAYLESS STAMPS—464-6463—Gerald Hawryluk provided excellent home service recently to a lady with ALS. Priced reasonably, and approved by the bank, this signature stamp maintains independence and ensures privacy. (Make sure you contact your bank for their approval) - and Thanks Gerald!

Ramp - 32 foot long, platform ramp with railing - 3-4 steps in height. Call 452-0458 for info.

La-Z-Boy Electric lift Recliner chair, model 1L598 Bridgetown, small. Cost \$2000. New. Used 3 months, soft brown colour. Asking \$1000. Call (780)875-7995 (Lloydminster)

Inspirational CD - 'Songs of Faith and Inspiration'

This contains a variety of songs, selected and performed by Louise Brown who has ALS. Louise lives in Saskatchewan, and visits us when in Edmonton. To order: contact this office at 487-0754 or, Louise at 306-761-2605.

Cost - \$15.00. Proceeds to the ALS Society.

Clothing for the Disabled

Kathy Sawatzky is quadriplegic and has a clothing company of outerwear and jeans. See these products on the web-site www.gakada.com or call toll free: 1 866 458-5651

Non Chew Cookbook - An excellent resource and tasty recipes.

Cost - \$32.50 US. Contact: 1-800-843-2409

Sample copy in the office.

CANGIVE.CA

The ALS Society of Canada and www.cangive.ca would like to inform you about a unique shopping portal. Cangive.ca enable on-line shoppers to make purchases in support of the ALS Society of Canada. The Cangive.ca web site is completely free to use. Please visit www.cangive.ca today for details. The Cangive.ca shopping portal has more than 60 leading online stores. Thank you in advance for your continued support.

ALS Society of Canada

BOOK REVIEW CRIES OF THE SILENT

by Evelyn Bell

This autobiography of Evelyn Bell's life gives great insight into the ALS journey as she begins her story from the moment of discovering the shocking diagnosis and then communicates the phenomenal range of emotions she experiences as the disease progresses. One of Evelyn's greatest desires was to communicate the challenges and frustrations of ALS in order to inspire the public to realize the need for more funding and research and she certainly persevered in doing her part by writing this book even through extreme challenges, especially in the latter stages of her ALS.

There were several things I really appreciated about this book, but one of

Evelyn's thoughts that I personally am adopting is her comment, "I was determined that I would not be bitter; I would be better." She demonstrated incredible courage to be open about her thoughts, feelings, and experiences and was committed to avoiding self-pity. She does an excellent job of sharing the emotional as well as the physical changes with incredible honesty. Another part of this book that I found helpful was the inclusion of some of her personal journal entries such as the letters she wrote to her sons. In a practical sense, it gives me ideas of various things I, too, would like to accomplish as I go through my own ALS journey. There is also one section of

this autobiography that would be helpful for family as well as caregivers of an ALS individual because Evelyn clearly explains many practical suggestions to assist with making the ALS person more comfortable, especially if communication skills have been impaired.

As I read Evelyn's story, I freely laughed and cried with her and loved her for her genuine and courageous expression of the range of emotions and experiences many of us are truly encountering on a daily basis.

Submitted by Joyce Pirnak

This book is available in the office @ \$12.00.

MESSAGE FROM Chris Yates, President – Edmonton Chapter Project Team

The ALS Society of Canada Symposium occurred in Toronto Oct. 25 - 27, 2002. Approximately 140 people from across Canada attended including ALS Society staff, volunteers, Healthcare professionals, and people with ALS. Speakers included Senator Sharon Carstairs, Dr. Arthur Hudson, Dr. Michael Strong, Dr. Jean-Pierre Julien, and Dr. Wendy Johnston. 42 workshops covered a wide range of topics. The ALS Society of Alberta and the Edmonton Chapter were well represented.

A major learning for me was about 'INFLUENCE' – a driving force of political decision making. We CAN influence parliamentarians to support legislation that would benefit to those trying to "make every day the best possible for people with ALS". Sharon Carstairs, The Leader of the Government in the Senate and Minister with Special Responsibility for Palliative Care - a keynote speaker - spoke passionately about her role in the Senate and her commitment to influence change and to improve the lives of people with debilitating diseases such as ALS.

I believe that we need to **SHOW** her that she is on the right track and that we **SUPPORT** this work.

The following are two points from the latest ALS Society of Canada Network and I urge each of you find the time to contact one or all of the members of parliament listed below to show your support and

express your thanks.

BILL C206

This private members bill, tabled by Nova Scotia MP Peter Stoffer, "proposing modification of existing federal government program to enable Canadians to leave their jobs to provide care for family members in palliative care or undergoing severe rehabilitation" will be debated in the House of Commons on January 29th at 5:30 pm. Catch it live on the CPAC channel.

You can show your support for this legislation by sending e-mail messages to the following:

- ◆ The Prime Minister - chretj@parl.gc.ca
- ◆ Minister of Human Resource Development - (the Hon. Jane Stewart) - stewaj@parl.gc.ca
- ◆ Minister of Health - (the Hon. Anne McLellan) - McLela@parl.gc.ca

HEALTHCARE REFORM - Saying 'Thank you'

The tabling of the Romanow Commission report (<http://www.healthcarecommission.ca>) and the recent speech from the Minister of Health (<http://www.hc-sc.gc.ca/english/>) clearly supports the key messages of the ALS Society.

- ◆ Development, funding and implementation of a multi-jurisdictional and comprehensive home care strategy that accommodates the complex and demanding needs of

Canadians with ALS and other diseases.

- ◆ The enabling of on-going caregiving by modification of existing federal government programs to enable those family members leave from employment without loss of income or job security.

Canadians from the ALS network have been asking for these policy changes for some time and a thank you from individuals to their own Member of Parliament is in order. We suggest writing to:

1. thank individual Members of Parliament (e-mail addresses can be found at - <http://www.parl.gc.ca/>) for making health care a priority, in particular homecare and compassionate leave;
2. urge their continued support of any legislation that might be brought forward in the coming months that addresses and implements these programs.

For those who do not have access to E-mail, the old fashioned regular mail service works just as well if not quite as quickly. Any member of parliament can be reached by addressing a letter to your own MP or any of the above to: The House of Commons, Parliament Buildings, Ottawa, Ontario K1A 0A6.

REVERSE MORTGAGE - TAX-FRIENDLY RESOURCE FOR SENIORS.

Preserve investments and government benefits by tapping into home equity tax-free.

Compared to other ways of accessing cash from your assets, a Canadian Home Income Plan Reverse Mortgage offers some unique advantages to homeowners 62 and older.

You pay no tax on the money from a reverse mortgage. That makes it a tax-friendly alternative to taking extra RRIF withdrawals or cashing in securities—choices that may increase your personal tax and put your government benefits at risk.

Unlike other home equity borrowing options, a reverse mortgage requires no repayment as long as you live in your

home. Instead, the principal and interest are paid when you sell your home or it becomes part of your estate. And repayment will never exceed the fair market value of your home at the time it is sold, protecting the balance of your assets. Tailor-made for seniors, a CHIP Reverse Mortgage can help you source extra cash from your assets with out paying extra tax.

Reverse Mortgage Facts

- ◆ \$20,000 to 500,000 tax-free
- ◆ No monthly payments
- ◆ No risk to government benefits

Call 1-800-639-9709 for more information

REMINDER - EQUIPMENT RETURN

If you have equipment you are not using, please return it so others may benefit. If you have questions, discuss with your OT or contact this office.

COMMENTARY ON ALTERNATIVE OR COMPLEMENTARY TREATMENTS

Extensive research is done for pharmaceutical drugs, little research has been done on "alternative" medicines with the exception of vitamins, which have been extensively researched. Many "alternative" medicines have been used by some cultures for hundreds and even thousands of years. We often hear stories of how people have been cured by these medicines and it is well known that animal and plant by-products have provided the basis for many successful drugs. Unfortunately, the hundreds of millions of dollars that are required to thoroughly test pharmaceutical medicines are not available to test "alternative" medicines. Scientifically, we know very little about the effect of "alternative" medicines on the human body.

If you are considering "alternative" medicines or therapies, here are some points to keep in mind:

- ◆ Be careful, some people who have ALS have been enticed into spending large sums of money on alternative medicines and therapies that carry false claims.
- ◆ Medicines that come from nature are, in fact, drugs and can be harmful, particularly in large doses. Different individuals have different tolerance levels for drugs, including so-called natural remedies. There are many products in nature, which are, in fact, poisonous.
- ◆ "Alternative" medicines are not regulated. The consumer is subject to domestic and foreign manufacturers who could dilute the strength, or change the composition of their products without disclosing this information on their labels.
- ◆ The ALS Society does not recommend that people take

"alternatives" and is not aware of any alternative medicines that will cure ALS. However, if you want more information about these types of medicines, it may be better to discuss the subject with professionals such as pharmacists, naturopathic and homeopathic doctors, rather than those who are untrained.

Because vitamins, herbs and other so called "complementary" or "alternative" medicines have become so popular over the last few years, it is timely to comment on these treatments in the context of research. People with ALS can be attracted to these apparent remedies, either because drug trials so far have been unsuccessful, or because of the perception that "alternative" medicines are natural.

*Source: ALS Society of Canada
Health Professional Advisory Committee
February 2002*

RESEARCH / COMMUNITY DEVELOPMENT

Men with Disabilities

Source: Alberta Committee of Citizens with Disabilities—
Winter 2002-03

Over the past few years, much of Alberta Committee of Citizens with Disabilities (ACCD) research has focused on the issues faced by women with disabilities. While we will continue our work in this area, the board would also like to direct some attention to the situations that are particular to men with disabilities.

On Wednesday, November 14, a focus group consisting of eight men with various disabilities met at the ACCD office to discuss issues that affect their lives. Many ideas were raised at the meeting; some of these include

- ◆ Young men with a disability are afraid of the image they portray when they go out into society.
- ◆ There is an expectation that men should be in the workforce.
- ◆ You need to be careful that relationships are partnerships. You don't want to just be looked after.
- ◆ It is hard to ask for help. This is true for all men, but becomes more important in the lives of men with disabilities.
- ◆ Many men's issues are not limited to men with disabilities.

The ACCD Board will review these and other ideas generated through the focus group and decide on a direction for the project. If you are a man with a disability and you have ideas to share with us about your experiences, please contact ACCD at 488-9088 (in Edmonton) or toll free at 1-800-387-2514.

KEEPING COVERED

Do you have trouble keeping the covers on when you are sleeping and have trouble pulling them up for yourself? Here is a helpful idea.

Use an elastic sheet garter to hold the top of the cover to the fitted sheet. This creates a sleeping bag and keeps the covers up while the elastic gives room to move.

FOUND

A sweat shirt has been turned into the office that was found at the Walk to D'Feet in September. It is from Evergreen Elementary School. If it is yours please contact the office.

CAREGIVERS WEB-SITE

www.enablelink.org

This is targeted to caregivers and supporters of people with disabilities: parents, husbands, wives, adult children, siblings, friends and any others who share their lives - and love - with someone with a disability. You are invited to come and discuss some of the challenges, frustrations and rewards you and your loved one experience, as well as share solutions and ideas. Connect and support and celebrate each other!

CONDOLENCES

Our sincere condolences to the families of:

Esther Hladych Jim Littlechilds Ray White
Sean Elchuk Cecile Majeau Lillian Kemp
Arthur Tollefsrud