



NEWSFLASH

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

January 2005

Quotes From The ALS Society OF Canada's 2003 Annual Report:

David S. Cameron, National Executive Director

Strength of Volunteers

"While a comparatively small number of Canadians live with ALS, the Society has many and willing volunteers who are dedicated beyond usual expectations. The nature of the disease is that people are motivated to become volunteers and to help in the efforts of the societies across the country to make a difference in the lives of those with ALS. We can be proud of the dedicated and long-term support our volunteers provide.

Fund Development:

This is a strong, financially healthy organization with a substantial reserve position to take us into the future. It is important for all of us as it allows us to plan for the next opportunities on the horizon as well as allowing us to continue our present work."

Bud Roberts, Treasurer

"As our awareness grows, our ability to fund raise increases; as we broaden our fund raising approach, we attract new donors to our mission; as we develop volunteer resources across the country, families with ALS have more support to manage their situation; as we mature as a voluntary organization, we attract strong leadership volunteers and excellent staff. "

March of Faces

There are currently 512 names and pictures on the ALS Canada web site. The March of Faces banners honor those living with ALS and those who have succumbed to the disease.

To participate in the ALS March of Faces call the ALS Society Office for forms, or contact George Goodwin by E-mail at george.goodwin@sympatico.ca or visit George's website at www.alsindependence.com.

ALS Canada Launches New Look for Walk 2005



When the Board of Directors of the ALS Society of Canada were presented with new licensing requirements to use the name "Walk to D'Feet ALS", the board made the decision to invest in an all new Canadian Logo and event to keep our funds in Canada. The new name for "the Walk" in 2005 is "**Walk for ALS**" (new logo above).

In gearing up for the 2005 Walks (to be held in June this year), ALS Canada will be hosting a training session on January 29th & 30th, 2005 in Edmonton and will pay for one **Walk Coordinator** from each walk site to attend. This training session is designed to give the **Walk Coordinators** an overview of the entire event process to make it as systematic and painless as possible to run and manage the event.

Anyone wishing to host a new "**Walk for ALS**" site on June 11th, 2005 and become a **Walk Coordinator** for the new site is encouraged to contact Wayne Steer, Manager, Resource Development toll free at 888-309-1111 or via e-mail at wayne@alsab.ca for more information and/or to register.

The "Walk for ALS" is an excellent way to involve your community and bring about better awareness of what ALS is and how the ALS Society of Alberta can help those living with ALS.

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.

ALS Society of Canada holds its First Research Forum

Toronto, October 12, 2004: The ALS Society of Canada hosted its first research forum October 15 & 16, 2004 at the Bank of Montreal Institute for Learning, 3550 Pharmacy Ave. in Scarborough.

The purpose of the forum is to consult with members of the Canadian ALS research community to review and recommend priorities and direction for the ALS Society of Canada research program. Our existing research program is primarily a collaborative initiative with Muscular Dystrophy Canada and the Canadian Institutes of Health Research.

In attendance were top Canadian researchers, and the next generation of young post-doctoral researchers -- with an interest in ALS research, including those funded by the Neuromuscular Research Partnership (NRP). The NRP is a partnership between Muscular Dystrophy Canada, ALS Society of Canada and the Canadian Institutes of Health Research (CIHR). In this partnership, each of the three organizations contributes an equal amount agreed upon each year and combines that with other CIHR funds to support leading Canadian neuromuscular research.

The keynote speaker on Friday, October 15 was Dr. Remi Quirion, professor and scientific director at the Douglas Hospital Research Centre – a McGill University affiliated teaching hospital in Montréal and Scientific Director at INMHA (Institute of Neurosciences, Mental Health and Addiction), CIHR. Dr. Quirion discussed the importance of partnerships in the scientific/research community.

On Saturday October 16, Dr. Neil Cashman, head of the Neuromuscular Clinic of the Sunnybrook & Women's College Health Sciences Centre and the University of Toronto, and Chair of the ALS Society of Canada's research committee led the group to help determine the areas of priority for research funding and to propose future initiatives and partnerships for ALS research. Senior scientists presented a brief synopsis of their work to date.

Funding assistance for this event was provided by the Institute for Neurosciences Mental Health and Addiction.

Excerpted from *Ontario Journals* Winter 2004

ALS Canada Awarded 2007 International Research Symposium

In late 2007 (November/December), the ALS Society of Canada will host the 18th International Symposium of ALS/MND in Toronto. This annual gathering brings together the top scientific and clinical minds in the world along with individuals with ALS and caregivers to discuss the progress of research towards care and cure for ALS. Having the Symposium in Canada will allow us to profile the superb work being done by the Canadian scientific community.

Excerpted from *Ontario Journals* Winter 2004

Walk To D'Feet ALS



The Alberta version of the 2004 Walk to D'Feet ALS was a great success, raising just over \$180,000. These funds are greatly appreciated and needed to serve Albertans living with ALS.

The ALS Society of Alberta has grown over the past six years to serve over 30% more Albertans. Services include support (information, referrals and home visits), equipment and assistive technology, support groups, awareness and education (including advocacy to governments and health care professionals) and finding a cure through contributing to cutting edge research.

"The marvelous richness of human experience would lose something of rewarding human joy if there were no limitations to overcome. The hilltop hour would not be half so wonderful if there were no dark valleys to traverse."

Helen Keller

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.

ALS Society of Alberta's New Manager, Resource Development

On October 18th, 2004, Wayne Steer joined the ALS Society of Alberta team as Manager, Resource Development.



Wayne comes to us from the private sector with over twenty years of experience in marketing, sales, business development and public relations with the Royal Bank of Canada, Husky Oil Marketing, Fantasyland Hotel at West Edmonton Mall and several small independently owned and operated businesses. He has engaged in various fundraising and volunteer coordination activities during a fourteen year period with organizations such as the Canadian Progress Club (Calgary and Edmonton), Uncles-At-Large/Aunts-At-Large, Big Brothers/Big Sisters, Calgary Burn Unit, Canadian Special Olympics, Camp Warwa Society, Canadian Mental Health Association and Rotary Clubs of Calgary (Rotary Challenger Park).

Wayne is looking forward to using his varied experience to help bring more awareness of ALS to Albertans and to work with our various clients, friends and families to find new ways to fund and fulfill our mission of "... making every day the best possible day for people with ALS by providing support, facilitating the provision of care, promoting awareness, and helping find a cure."

North Region Open House

The ALS Society of Alberta, North Region, held an open house for clients, volunteers and health professionals on December 8th, 2004. Although the weather was cold, about 45 individuals attended. It was a great success!



Dan Hein and Carl Yuzel at the Open House

ACRES FOR ALS, HARVEST OF HOPE



Spring of 2005 will see us working with our sister units in Manitoba and Saskatchewan on the "**Acres for ALS, Harvest of Hope**" campaign. This campaign was piloted in Manitoba in 2004 in response to the realization

that there were a great number of individuals, families and communities in rural settings living with ALS with no structured opportunities for rural communities to show support for them.

Acres for ALS, Harvest of Hope involves farmers, literally at the grass roots level, who pledge the proceeds of one acre of the 2005 crop at planting time and remit the money to the ALS Society of Alberta for a tax deductible receipt once the crop has been harvested.

This program does much to give the rural community a way to become actively involved in supporting and spreading awareness of the services that the ALS Society of Alberta offers to people living with ALS, as well as to families and friends living in rural Alberta.

Currently an inter-provincial committee is planning events throughout the Prairie Provinces to kick off, promote and celebrate the campaign. The committee is currently looking for suitable businesses to be sponsors as well as information hubs for this program.

For more information on how you or someone you know can become involved in this exciting program please contact Wayne Steer, Manager, Resource Development toll free at 888-309-1111 or by e-mail at wayne@alsab.ca.

THANK YOU!!!

North Region staff would like to thank all who sent cards, attended the Open House, and who brought seasonal goodies to the office. Your continued support and gracious spirits keep us going. Thank you very much.

"In the depth of winter I finally learned there was in me invincible summer."
Albert Camus

NORTH REGION NEWS

Advocacy Committee

A busy 2004, included the successful Day at the Legislature in April when 50 volunteers from across Alberta met with 49 MLA's to increase awareness of ALS and discuss Equity of Access to programs and services. Meetings have since occurred with Standing Policy Committee on Health and Community Living, and a number of other key policy staff. Movement towards positive changes are apparent.

There is now more work ahead of us. A second survey will be sent out shortly, to again seek input about your needs and issues. This committee depends on your feedback to ensure that advocacy efforts result in meaningful changes.

If involvement with the Advocacy Committee appeals to you, please call 780-487-0754, or Cathy Martin at 780-463-4905, or e-mail: cathy@alsab.ca.

Complimentary Or Alternative Medicines

Natural health products (NHP's) are defined as: vitamins, minerals, herbal remedies, homeopathic medicines, traditional medicines, such as Traditional Chinese Medicines, probiotics and other products like amino acids and essential fatty acids.

Health Canada has adopted the new Natural Health Products regulations under the Foods & Drugs Act.

Consumers Benefit by information on:

- Increased label and adverse reactions information
- NHP's now require a product license number or NPN or DIN-HM indicating review for safety and usefulness.
- Standards of evidence – history, studies and clinical trials.

Visit www.hc-sc.gc.ca/hpfb-dgpsa/nhpd-dpsn/index_e.html

Excerpted from Fact Sheet # II - www.als.ca

Our Sincere Condolences to the Families of:

South Region

Vera (Bobby) Harris
John Fox
Mike Adams
Phil Fukuda
Marion Hopkins

North Region

Roland Schultz
Fred Rowbotham
Rodger Lien
Thomas Fisk
William Sturgeon

Donations

The Edmonton Realtor's Charitable Foundation donated \$90,000 to 20 different agencies. The ALS Society of Alberta, Northern Region, received \$4,000. These funds will be used for equipment to provide access to and from homes. Thank you Edmonton Realtor's Charitable Foundation for your generosity!



Patricia Ordynec, Manager, North Region ALS Society with Bruce Gaetz, President, Edmonton Realtor's Charitable Foundation

Good-Bye & Hello

Farewell & thanks bid to Lisa Andruchiw. North Region Office.

Phyllis Javorsky was welcomed and introduced as the "New" Administration & Volunteer Services staff. Phyllis brings experience in the non-profit sector at Muscular Dystrophy Canada as well as a Degree in Community Rehabilitation. It's good to have you aboard.

Volunteer Questions

Please contact Phyllis at the ALS Society
At (780) 487-0754
North Region Toll Free 1-866-447-0754
E-mail: phyllis@alsab.ca

Many things are lost for want of asking.
English Proverb

Tips – U of A, ALS Clinic

To Call? or Who to Call? that is the Question

There is often a multitude of health care providers involved in the care of an ALS patient. This can be confusing and frustrating for the ALS patient and their family when concerns arise and they are not sure who to contact. The following guidelines may provide some help in making this decision.

If the medical concern is likely not related to ALS, it is best to contact your family doctor. This could include concerns such as flu, colds, urinary tract issues, or injuries from falls.

For medical concerns associated with ALS, for example, breathing changes, excess saliva, weight loss, swallowing or speaking difficulties or anxiety, please contact the ALS Clinic.

Some symptoms such as headaches, muscle spasms or cramps may or may not be part of ALS. If you are unsure, contact the ALS Clinic for advice at (780) 407-3718 or (780) 407-3719

Road Of Life

The road of life is short and narrow,
 Sometimes full of pain,
 Sometimes lots of sunshine,
 Sometimes lots of rain,
 GOD didn't promise it to be easy,
 But promised us all his love,
 If we stray away from him,
 We will not have his riches,
 That he promised from above.
 The trials and tribulations,
 That we so often face,
 Makes our road of life so difficult,
 That we want to give up the race,
 Just when our burdens seem too heavy,
 And it seems that no one cares,
 That is when God listens,
 To our silent prayers.
 So when you feel alone and downhearted,
 Just remember one little thing,
 In all of God's great creation,
 Even the smallest birds,
 Have all the reason to sing.

Submitted by: Jerry (Gerald) Braun

In Touch – Sue Decker, SLP

North Region

Now it's my turn! In this column, I am going to talk about how important it is for *me* to stay in touch with *you*. There are three important reasons that I take an active role in keeping in touch: relationship-building, carefree follow-up, and single point of contact.

Relationship Building: Communication loss is a very personal journey. Many clients have several different transition points in their communication needs as ALS progresses. For example, there is a transition when people can no longer use speech clarity strategies to be understood and an alternative communication system is needed. I notice I am the most help in making those transitions smoother if we have a relationship before transition actually happens.

Carefree Follow-Up: Dealing with day-to-day care, appointments, and coping with ALS is time and energy consuming. Remembering to call the speech therapist when there is a change in communication does not always happen. That's why I check in by e-mail or phone with many of you on a regular basis. Feel free to say "Don't call us, we'll call you" at any time if you do not want active follow-up with me.

Single Point of Contact: There may be many different speech therapists involved with you. There are times that clients need me to be the "point-person" in the system. I take on the role of keeping in touch with all of these professionals when it comes to swallowing and communication needs. In the areas outside of the Capital Region, I am often in regular touch with the speech therapist and other professionals in the area to make sure they are getting the support they need to follow-up with you and your family. It is my privilege to serve you however I can and to keep you in touch with your loved-ones.

INCOME TAX INFORMATION

Income Tax Form T2201 – Disability Tax Credit form – is available on line at www.cra-arc.gc.ca
 Go to Forms, T2201, available in PDF or e-text format; or phone 1-800-959-8281.
 Eligibility of a prolonged impairment must be certified by a qualified person. Please contact your accountant or tax processor.
 Copies are available in the North Region Office.

COMMUNITY RESOURCES

Capital Health Authority Community Rehabilitation Program Edmonton General Hospital Continuing Care Centre Phone: 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.

Equipment

Please return any equipment you are not using, so that others may benefit. The ALS Society loan cupboard is continually growing to serve your needs, and may accept donations of privately purchased items that are appropriate. Tax receipts may be available. For more information call your local ALS Society Office.

Chat Room

The International Alliance of ALS/MND Associations has a chat room available to anyone who wishes to discuss ALS matters. The address is as follows:

www.alsmndalliance.org

Attention Caregivers

Alberta Caregivers Association
14220 – 109 Avenue
Edmonton, Alberta T5N 4B3
Tel: 780-447-9224
Fax: 780-488-3561

www.AlbertaCaregivers/Association.org

ALS Clinics

ALS Clinic – North Region	780-407-3718,
Research Coordinator	780-487-3719
ALS Clinic – South Region	403-943-2343

Edmonton - IN HOME FOOT CARE

The Edmonton Foot Health Care Centre provides in home foot care. For more information, contact the Edmonton Foot Health Centre, 12211B – 97 Street, Edmonton, AB T5G 1Z2. Tel: 1-780-474-3338 or Fax: 1-780-471-3738

Traveling?

Find out more about 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 to a person with a permanent disability allow an accompanying adult attendant to travel at no cost.

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

Alberta Seniors

SPECIAL NEEDS ASSISTANCE FOR SENIORS

A special Needs Assistance For Seniors program provides assistance to eligible lower-income seniors who are experiencing financial difficulties (Annual income below \$18,745 for single and \$28,530 for couple). Contact the Alberta Seniors at: 1-800-642-3853.

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"