

# Coast to Coast



Fall 2007

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## HIKE 4 ALS



Participants in the 2007 Hike 4 ALS gear up for the 10km Hike at the Kortright Centre in Vaughan, Ontario.

The ALS Society of Canada and ALS Society of Ontario hosted the 3rd Annual HIKE 4 ALS at the Kortright Centre for Conservation in Vaughan, north of Toronto, on September 29th 2007, during Ontario Hiking week.

This year's hike was the most successful yet, with more than 250 participants raising \$67,000, which will be shared equally between ALS Canada and ALS Ontario. A prominent team hiked for Dr. Heather Houston, an obstetrician at York Central Hospital who was diagnosed with ALS in June. Houston's friends, family and co-workers were there to show their support.

Compared to previous years, participation for the hike has doubled, along with donations. "Growth in participation means growth in awareness. This is what's important," says David Cameron, president and CEO, ALS Society of Canada. "It was wonderful to see so many families and so many

children taking part in such a significant event."

The HIKE 4 ALS is one of the signature events of the ALS Society. The money raised funds desperately needed equipment and support services for people living with ALS, as well as research for a cure. These services increase the quality of life for people living with ALS by providing them with independence, dignity and choice, while ALS research provides them with hope for the future.



## REPORT FROM THE CHAIR OF THE BOARD OF DIRECTORS AND THE PRESIDENT & CEO



Left to right - Ben Wendland, Chair, Board of Directors and David Cameron, President & CEO

The past several months have been very busy and productive for ALS Canada in the areas of fundraising and awareness building. The supplement published in the April 26<sup>th</sup> edition of *The Globe and Mail* signaled the start to an extremely busy summer. The supplement discussed the devastation caused by ALS and the hope that research gives to people with ALS. It also contained personal stories, researcher profiles and information about the WALK for ALS.

The 2007 WALKs for ALS were very successful. Most of the Walks took place in June as part of ALS Awareness month. Across the country thousands of volunteers came out for

the Walks, raising more than \$2 million for research and people living with ALS. The WALK for ALS is our signature event and this year's turnout was inspirational for everyone who took part and witnessed the extraordinary efforts made by the participants.

The ALS Charity Golf Classic in memory of Tim Noël was held June 26, at the Sleepy Hollow golf club in Stouffville. Tim Noël was the former deputy governor of the Bank of Canada and died of ALS in July 2001. The funds raised this year will continue to support a post-doctoral research fellowship in Noël's honor. This year the tournament raised more than \$23,000.

The Canadian Neurological Sciences Federation (CNSF) hosted its 42<sup>nd</sup> Annual Congress in Edmonton, Alberta from June 19-22. Denise Figlewicz, PhD, our director of research, spoke about advances in basic science. Many of the ALS Canada staff attended presentations and discussions such as: ALS strategies for quality of life/quality of care; advances in clinical care; advances in basic science; discussing hope with ALS patients and families; and what's new in ALS.

The 4<sup>th</sup> Annual ALS Client Services Conference took place on June 19 and 20 in Edmonton. It brought together clinical-care professionals and ALS Society staff from across the country involved in service delivery to share information, good practices and innovative ideas. Topics included: advanced care planning; children and grief; working together to respond to the needs of persons with ALS and other groups; and compassionate listening. The most valuable part of the conference was the opportunity for participants to network and learn from others working in ALS clinics and Societies.

The third annual HIKE 4

ALS, in partnership with the ALS Society of Ontario, took place September 29, 2007 and raised \$67,000. Although still in its early years, the Hike shows great promise for the future as a growing fundraiser.

Looking forward, December 1-3, 2007, we will host the 18<sup>th</sup> International Symposium on ALS/MND. The symposium brings together researchers, health and social care professionals, and people with ALS from around the world to present and discuss new innovations. This is the first time this conference will be held in Toronto and we are very optimistic about the opportunities this will give us to raise awareness.

Together we are making a difference in the lives of people with ALS. The fundraisers, volunteers and everyone who educates a friend about ALS make a difference. Your support and dedication make the hope created through research possible.

## 2007 WALK for ALS

The WALK for ALS is our signature national fundraising and awareness building event and 2007 has been a very successful year for us. Across the country more than 65 communities rose to the challenge to organize a WALK for ALS and more than \$2 million was raised by the end of September.

The involvement of Zack Werner, *Canadian Idol* judge and successful Canadian music executive, as the

national WALK for ALS chair and spokesperson again this year helped our efforts to raise awareness of ALS. More than 80 stories about the Walk appeared in newspapers nationwide. Many articles featured the personal stories of people with ALS and their families.

ALS Canada uses 40 per cent of the money raised to fund research towards a cure for ALS. The other 60 per cent goes to the

provincial Societies who use it to organize local health care, community services, educational information, equipment assistance, home-visits and co-ordination of peer support groups.

President & CEO of the ALS Society of Canada David Cameron says, "When the WALK for ALS started in 2001 there were only five communities involved and this year we raised more than \$2

million with the Walk. That kind of growth in such a short time is remarkable and very encouraging for the future. The dedication of the volunteers who have raised this money and walked for ALS makes it possible for us to fund the research that brings hope and to supply the equipment and support that brings comfort to people living with ALS."

## Highlights from the Walks

### Fraser Valley, British Columbia

Approximately \$40,000 was raised at Fraser Valley's inaugural WALK for ALS, more than triple their original expectations. Wheelchair Olympian Eugene Reimer participated and was the first person to finish the Walk. Patty Walman, diagnosed with ALS three years ago, told reporters, "The only hope we have is research. I want people to donate, donate, donate!"

### Red Deer, Alberta

Iris Powell helped start the first Red

Deer Walk in 2004 and has been a driving force behind it since. She passed away before this year's Walk could be organized. In her memory, her husband, Wayne Powell, took over the reigns. His goal was to raise \$7,000 personally and for the Red Deer Walk to surpass last year's total of \$65,000. One of the Walk participants, Bob Heinz says, "We're just hoping some day the funds that come in will help researchers find a cure." He feels that although money for research and equipment is important, the most important aspect of the Walk is the hope it brings for the future.

### Miramichi, New Brunswick

In 2003 Lynn Beaulieu was the only walker, raising \$800. This year more than 50 people walked with her and Beaulieu believes that the number

of walkers will keep growing and, in turn, so will awareness of ALS.

### Burin Peninsula, Newfoundland

Mary Lundrigan hoped to more than double the \$2,000 raised in Burin Peninsula's Walk last year. Lundrigan's brother-in-law was diagnosed with ALS in 2005 and she says that organizing a local Walk was her way of dealing with it. She hopes the money raised will help find a cure, help people living with ALS, and raise awareness amongst the public.

### Scotchtown, Nova Scotia

For the 275 walkers in the second annual Scotchtown Walk the fun didn't end when the Walk was over. They had entertainment, face painting, prizes, barbeque and a big bounce tent for kids. Sharon and Deborah MacKay estimate the Walk raised more than \$5,000 this year.

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**Wingham walkers pose for the camera.**  
Published with permission of  
The Wingham-Advance Times

## Highlights from the Walks

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### Cornwall, Ontario

In its fourth year the Cornwall Walk had more than 300 participants and raised \$44,000. "This year's Walk exceeded all of our expectations," says Kimberly Walsh, chairperson for the Walk. The Walk was a family event offering breakfast and face painting for children.

### Prince Albert, Saskatchewan

Last year the Prince Albert Walk raised \$7,000 and this year approximately 40 people raised more than \$10,500. A team of local children called the Blueberry Squad raised \$119.70. Twelve-year-old team member Kristen Goetzen described the Walk as "lots of fun."

## ALS Society of Canada elects new Chair

Effective April 28, 2007, Benjamin S. Wendland was elected to chair of the board for the ALS Society of Canada

Wendland's previous experience in human resources and management will be a great asset to the ALS Society of Canada as it strives to increase awareness and support for individuals diagnosed with the disease, as well as raise funds for ALS research.

Wendland's main goal as chair of the board is to continue to promote a sense of unity within the organization. "I want to foster a stable, smooth running organization. It is not common enough to find not-for-profits which are fulfilling their current mandate and enjoy peace and harmony internally," says Wendland.

Wendland has also been involved in numerous other volunteer endeavors including his current efforts as director for Millennium Relief and Development Services (Canada) and international director for Watoto Childcare Ministries in Uganda, Africa. Wendland is also a board member of the Christian Life Assembly.



For the past eight years, Wendland has been a key member of the ALS community, where he has held the positions of president and executive member of the ALS Society of British Columbia. During his time with ALS BC, he initiated strategic planning processes with the staff to best determine patient needs, pursued

high-profile business people to join the board, and helped create a public service announcement for ALS, which was awarded the BC Association of Broadcasters "Humanity" Award in June of 2002.

Currently, he is the CEO of Mainly Marine Closures Ltd., a manufacturing company for marine doors, hatches and windows.

He is also the president of Protec Management Ltd., a consulting company with a wide-range of involvements including the high-tech industry, small businesses and commercial development. At Protec Management Ltd., Wendland consults with small- to medium-sized businesses in team building, human resources and sales management issues.

Wendland, who is married with three children and one grandchild, resides in Langley, BC.

## Annual Report wins Award

The ALS Society of Canada received a Gold Hermes Creative Award for its 2005 Annual Report, *Hope and Help*. Recipients of the Gold Award are those "judged to exceed the high standards of the industry

norm." The Annual Report was evaluated based on its concept, writing and design quality and creativity. Of the more than 3,500 entries that were submitted approximately 18 per cent received the Gold Award.

The Hermes Creative Awards is an international competition for creative professionals involved in the concept, writing and design of marketing and communication programs and print, visual and audio materials.



## Alberta Hospital Wins Team Award for ALS Care

A multidisciplinary ALS team at Misericordia Community Hospital in Edmonton has won the Caritas Health Group Team Mission Award for its innovative and holistic approach to treating the disease.

The award is granted annually to a team for outstanding contribution to Caritas Health Group's mission and values using creativity,

innovation and resiliency and for positively impacting and improving the quality of life of individuals.

The ALS team was established in 2005 by respirologist Mark Heule and neurologist Wendy Johnston to provide a solution to the complex challenges faced by people with ALS. With their colleagues they pioneered a program offering breathing support, physical and occupational

therapy, speech-language pathology, nutrition support, social work and pastoral care.

"The ALS clinic made all the difference in the world because they're so up-to-date. They know what patients need," says Ann Lund, who lost her husband to ALS.

"We educate, encourage and support home, palliative and long-term staff

care in the patient's community. This is a challenge due to our geography, but not unusual in Canada," says team member Sonya Wheeler, a respiratory therapist.

Approximately 50 per cent of their 80 patients reside outside Edmonton. Because travel becomes more difficult as ALS progresses, the clinic offers Telehealth services to patients and their families.

## BOOK REVIEWS

### Palliative Care in ALS: From Diagnosis to Bereavement

Written by a team of international ALS experts, *Palliative Care in Amyotrophic Lateral Sclerosis: From Diagnosis to Bereavement*, 2nd Edition, applies recent ALS research to palliative care techniques. It is the only book to focus specifically on palliative care for people with ALS.

The authors argue that because there is no cure or effective treatment for ALS, palliative care is integral to the clinical approach to the disease. The book discusses issues such as symptom control, occupa-

tional, physical and speech therapies, pastoral care, advance directives and end of life care. It is a practical guide to daily care for members of the multidisciplinary palliative care team. Neurologists and general practitioners caring for people with ALS will also find it a useful resource.

Edited by David Oliver, Gian Domenico Borasio and Declan Walsh, *Palliative Care in Amyotrophic Lateral Sclerosis: From Diagnosis to Bereavement*, 2nd Edition, is published by Oxford University Press. The book can be purchased at amazon.ca for \$43.44.

### You're Not You

Based on an earlier short story, Michelle Wildgen's *You're Not You* delves into the patient-caregiver relationship in an unexpected way.

For Kate and Bec, the relationship is defined as one of mutual need and attachment. Bec is an indifferent university student searching for experience and direction when she accepts a position as caregiver to 30-something Kate, a former advertising executive stricken with ALS.

Despite her physical limitations, Kate is presented as a whole person: intelligent, witty, sophisticated, stub-

born and bold. Kate wants to retain control of her care, a point of contention for her husband and parents. As the novel unfolds, the reader sees the struggle between Kate's awareness of her worsening condition and her fight against this realization. A similar struggle occurs in Bec as she transforms from an aimless, uncertain young adult to a confident, purposeful woman.

A story of friendship, awakening and pain, *You're Not You* is published by Picador Press. It is available for \$17.50 at most major bookstores.

## 4th Annual ALS Client Services Conference

The ALS Society of Canada hosted its 4th Annual Client Services Conference on June 19 and 20, 2007 in Edmonton, Alberta. The conference was designed to bring together clinical-care professionals and ALS Society staff across Canada involved in service delivery to share information, good practices and innovative ideas.

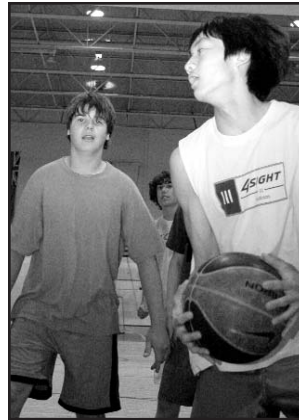
Jane McCarthy, director of services and education at ALS Canada says, "Providing this conference enables the ALS Society of Canada to play a key role in facilitating and promoting quality ALS services and care across the country."

An array of topics was covered, including: home feeding tube programs, bi-level ventilation, children and grief, working collaboratively to respond to the needs of persons in the community, equipment programs, sexuality, and compassionate listening.

McCarthy says, "The conference this year built on the success of last year's meeting as evidenced by an increased number of attendees. A 22 per cent increase in one year is significant. As in past years, the most valuable part of the conference was cited to be the opportunity to network and learn from others working in ALS clinics and societies."

The attendees were extremely enthusiastic in their feedback with many praising the breadth of topics covered and requesting that the conference be longer next year. There was also a lot of positive feedback about the group sessions and willingness of speakers to answer questions.

## Fundraising Highlights



**Students at Roland Michener Secondary School in Timmins, Ontario stayed up all night to raise money for ALS.**

**Photo courtesy of the Timmins Daily Press.**

Students at Roland Michener Secondary School in Timmins, Ontario stayed up all night on June 8 to raise money for ALS. Held the night before the annual WALK for ALS, students could donate a minimum of \$30 to participate in fun activities all night. They were supervised by staff members and bused to the Walk location the next day. The students raised more than \$1,800 for ALS.

Adam Cholmondeley believes a cure can be found for ALS if we raise enough money for research. The 11-year-old used his web site, <http://www.als.ca/even>

[ts/mysite.aspx?fid=1153](http://www.als.ca/even/ts/mysite.aspx?fid=1153), to tell his story and raise more than \$5,000 for the Kingston WALK for ALS. His school, Welborne Avenue Public School, raised more than \$1,700. His dad has ALS and Adam says, "ALS is a disease that ALWAYS LEAVES SADNESS so we need to find a cure so that anyone with ALS can be cured and the sadness lifted away."

Mark Garrish from Calgary, Alberta hasn't had a traditional birthday party the past two years. Instead, he celebrates continuing to live each year with a fundraising party in support of the ALS Society of Alberta. Garrish, with the support of his friends and family, raised more than \$80,000 this year through donations, door prizes, raffles, silent auctions and Betty's Run for ALS. The PowerPoint presentation they used at the fundraiser can be viewed on You Tube at <http://www.youtube.com/watch?v=yZeWWJHTV1g> or search You Tube for 'Garrish ALS'.

On June 15 at Château

Vaudreuil in Quebec, Hélène Pelletier hosted her second Gala of Hope. The event, which included cocktails, dinner, dancing and a silent auction, raised \$140,000 for ALS research. Pelletier's experience in the pharmaceutical industry taught her how research can turn a fatal disease into a chronic one. The \$120,000 raised last year created a clinical fellowship at the Montreal Neurological Institute.

On August 9, on the other side of the world, Michel Guay raised money to help the ALS Society of Quebec. His goal was to raise \$5,000 by climbing to the top of Tanzania's Mount Kilimanjaro. Guay was inspired to climb the mountain for ALS after losing two close friends to the disease.

Ray and Mary Steele of Nova Scotia have been collecting millions of pop can tabs and selling them to scrap yards for nine years.

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## Fundraising highlights

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For the last two years their proceeds have helped the ALS Society of Nova Scotia, with every 90 pounds of tabs yielding just under \$5.

The Flaming Mommas hockey team of North River, PEI raised more than \$8,000 for ALS at a charity game last February. Player and team manager, Maureen MacNevin, lost her husband to ALS. MacNevin, an ALS Society of PEI volunteer, says, "The rink was packed to standing room only, and the community support was spectacular." They are planning another hockey fundraiser for February 2008.

In Nova Scotia the girl who walks on her hands was at it again this year. On June 2, gymnast Catherine (Cat) Kennedy tumbled and walked on her hands for three kilometers - triple last year's distance - for ALS. Friends and family walked beside her to raise awareness and explain to passersby what she was doing. In the last two years she has raised approximately \$4,000.

British Columbia's ALS Adventure Challenge encourages participants to run, bike and kayak a combined distance of 17 kilometres to raise funds for ALS. This year marked the fourth Challenge in Vancouver and the first in Nanaimo. Together, they raised more than \$170,000. Participants receive training in the months leading up to the challenge and are asked to raise at least \$250 before race day.

In British Columbia, 46 professional golfers played more than 8,000 holes of golf to raise money for the ALS Society of BC. The Golf-a-Thon began in 2005 when Bruce Edwards, caddy of famed American golfer Tom Watson, was diagnosed and eventually died from ALS. The first event raised \$50,000 and this year they expect to triple that by raising \$150,000.

In Ayr, Ontario, Heather's Hootenanny for Hope raised more than \$35,000 in support of ALS. Heather Snell's life-long love of music inspired the musical theme to this

fundraiser that featured silent and live auctions, children's activities and a variety of musical entertainment. Zack Werner, WALK for ALS chair and national spokesperson and *Canadian Idol* judge, made a special appearance.

The British Automobile Touring Association of Nova Scotia (BATANS) held its second annual ALS LiveDrive fundraiser on October 14, with proceeds going to the patient support fund of ALS Nova Scotia. Participants paid \$1 per minute for a minimum 15 minutes to be driven around in an antique car. Last year the event raised more than \$1,000 and they hope to do even better this year.

## VFS Team Hits the Road for ALS

The Vancouver Film School (VFS) and ALS Societies across Canada are cheering on the creators of the Cannes-winning documentary *Documenting Charity (and the Art of Street Shaving)* as they embark on a cross-Canada charity fundraising tour, the ALS Ride Across Canada.

Glen Tedham, an instructor in VFS's Film Production program, his wife Jeannie, VFS instructor Megan Bodaly and VFS grad Aaron Beckum created the original five-minute documentary in one day as part of a contest for the Cannes Film Festival. The film, which asked the question, "What can you do in one day?" and sent Glen and Jeannie to the street, selling hugs to passers-by, won first prize in the contest at Cannes and raised \$530.62 for the ALS Society of BC. VFS matched the funds raised by the team and subsequent media coverage of the film's win led to another \$7,000 in donations from the public.

Now Glen and Jeannie are taking a Harley Davidson motorcycle - with sidecar - on the road to raise awareness and funding for ALS, also known as Lou Gehrig's Disease.

"Through this process, we have truly discovered what ordinary people can accomplish if they set their minds to it," Glen says.

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## VFS Team Hits the Road for ALS



Jeannie and Glen Tedham

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"We have been so inspired by what we accomplished in one day that now we have committed to continue our fundraising efforts for this disease"

"Our goal is to raise both awareness and funds for the ALS Society of Canada and the provincial ALS societies," explains Glen.

The ride began in St. John's, Newfoundland on September 11th and culminated in Vancouver, BC on

October 24th.

The team will produce a feature-length documentary about the ALS Ride Across Canada, which will also be entered in the 2008 Cannes Film Festival.

## ALS Advocate Inducted Into Terry Fox Hall of Fame

**E**lizabeth Grandbois, an ALS advocate living with the disease, was inducted into the Terry Fox Hall of Fame in recognition of her efforts to increase public awareness and improve quality of life for others afflicted by ALS.

Grandbois will be inducted as a Builder, a person who improves the quality of life for physically disabled people through science or medicine, advocacy, education, employment and housing.

"The induction into the Terry Fox Hall of Fame recognizes people who have made a difference and opened doors for people with disabilities. People who, like Terry Fox, are an inspiration to us all," says Vim Kochhar, Canadian Foundation for Physically Disabled Persons (CFPDP) chair.

Since her diagnosis in 1997, Grandbois has raised funds for research, treatment and awareness of ALS.

In 2001, she founded Elizabeth's Concert of Hope. After five successful years in Hamilton, Ontario, Grandbois took her concert on tour across Canada in 2006. The event has raised \$2.5 million for ALS research and patient services.

Grandbois has been featured in national publications and documentaries, including *Elizabeth's Hope*, seen by more than 7,000 viewers internationally. In 2004, she received the Governor General's Meritorious Service Award for her contributions to ALS fundraising and public awareness campaigns.

"Elizabeth's passion and determination make her a relentless force for

those silenced by ALS," says Paddy Torsney, former Member of Parliament for Burlington.

The induction ceremony took place November 5, 2007 in Toronto.

The Terry Fox Hall of Fame honors Canadians who have made significant contributions in assisting or enhancing the lives of the physically disabled. It was founded by the CFPDP and opened at Metro Hall in Toronto in 1994.





## Hope

By: *Leeza Limenis*

ALS remains a devastating and irreversible disease that tends to leave people with little time and even less hope. In the face of its debilitating nature, medical professionals, caregivers and patients continue to search for a cure. Sunnybrook Health Science Centre's multi-disciplinary ALS Clinic provides services to ALS patients in the hopes of improving their quality of life and independence. For a disease so dreadful and inexplicable, care in the form of social support and comfort optimization is especially valuable.

I recently had the privilege to accompany the clinic co-ordinator, Myrna Moore, on a home visit. A peek into how people cope with their situation at home from day-to-day sheds light on a type of life that is difficult to imagine during a patient's visit to the clinic. Beyond that, what truly breaks through from behind the damaged nerves and sometimes broken spirits is the real person inside.

It was through this visit that I learned about a 59-year-old female who was diagnosed with ALS three years ago. Having suffered from a duodenal ulcer at age 21 and having been previously diagnosed with cer-

vical cancer in her late 30s, she seemed preoccupied by her apparent "stream of bad luck". What she described as a slight weakness in her left foot in September 2003 after having trouble completing the Terry Fox Run has now taken the form of significant weakness and near absence of mobility in her lower limbs.

In addition to her frustration with the irreversibility and progression of her disease, there are other obstacles with which she must cope. Her home is in need of many renovations that will be both cumbersome and costly. A number of steps and ledges at entrances into the home and its bathrooms will need to be remodeled to be more wheelchair-friendly. Moreover, her home may also require a customized stair glide and a main-floor bathroom with a roll-in shower, two costly endeavors for the patient and her husband to manage.

What appears to combat the frustration and helplessness she feels is a passionate determination to live. Dissatisfied with the one agent currently approved for treatment, the patient has pursued a variety of expensive alternative therapies and

drug trials. Her initiative and persistence are coupled with what may be the best medicine currently available for ALS: a strong support network. As her husband's career requires him to be away from home frequently, she is fortunate to have many friends in her neighborhood who are happy to check up on her and lend a hand when needed.

Myrna Moore's home visit provided the patient with further information regarding social and medical resources, including hospice, Community Care Access Centres and ALS Society contacts and support networks. By discussing her situation in length, she shared with us the state of her disease, her current lifestyle and her outlook on her future. Unlike many others, she is fortunate to have a slowly progressing form of ALS, strong social support and the courageous spirit of a fighter. It appears that her "stream of bad luck" is countered by one powerful source: hope.

*This past summer Leeza Limenis worked under the supervision of Dr. Gavel and Dr. Zinman at the Sunnybrook ALS Clinic in Toronto.*

## ALS CANADA

It has been said that, "A volunteer is a person who can see what others cannot see; who can feel what most do not feel." On April 28th the ALS Society of Canada held its annual awards night to recognize volunteers across Canada for their exceptional contributions to the ALS Society in 2006.

## Ishtar Gabriel Exceptional Support Services Program Award



Gabriel understands the devastating emotional impact of ALS and has worked in many ways to help families carry on.

The mentorship program she co-ordinated has helped caregivers, spouses and children to find emotional strength and hope by talking with other people who have been in the same situation. Tim and Beth Robertson nominated Gabriel for this award in response to the incredible care she has shown them,

their family, and others. They say, "When she listens to our worries, or solutions we have found for certain problems, we know that she will take the information and suggest ways to help us, and use our experience to help someone else."

The Exceptional Support Services Program Award

recognizes an exceptional support service program in 2006. Support services include, educational programs designed for people involved with ALS, services that enhance the quality of life of people with ALS or their caregivers and programs that work with a clinic or community-based organization.

## Donna Wilson Exceptional Public Awareness Award



Wilson has been involved with ALS since Ron Krane, her radio co-host at Arctic Radio, lost his voice shortly after being diagnosed with ALS. For years she has helped create awareness about ALS in Thompson,

Manitoba, and, as Walk captain, increased participation in the local WALK for ALS. In 2006 she raised the bar by creating two PSAs, featuring "Walk On" by the popular rock group U2, that were used nation-

wide to increase awareness of and participation in the WALKs for ALS.

## Tim Spelliscy and Global Alberta News Team Exceptional Public Awareness Award (group)



Since 2001 Spelliscy and the Global Alberta News Team have been generously giving their time and their expertise to help raise awareness. Chris Yates' nomination letter reads, "Their help and recom-

mendations on how to maximize media attention and recognition proved to be invaluable." The help of Spelliscy and the Global Alberta News Team has been beneficial to the development and growth

of the ALS Society of Alberta. The PSAs, TV spots, and interviews that they have produced, in addition to their attendance at events over the years, have been a phenomenal boost to the Society.

# VOLUNTEER AWARDS

## Carrie Smith - Mary Pollock WALK for ALS Volunteer Award



Smith's best friend is her older brother Mike, and when he was diagnosed with ALS at 33, four days

after the birth of his first children (twins), Smith took action. One of her nominators, Shirley Smallwood, says, "Although she had never fundraised in the past, Carrie knew the love she had for her brother would be enough to carry her through. As a result, she put her heart and soul into

making the 2006 Moncton WALK for ALS the most successful ever." In 2006 Smith more than doubled the funds raised by the 2005 New Brunswick WALK for ALS, raising a total of \$43,000.

The Mary Pollock WALK for ALS Volunteer Award is given annually through

the generous support of the Pollock Family. It honors Mary Pollock, who died of ALS in 2000. The award recognizes and celebrates outstanding contributions and achievements by a volunteer in developing a Walk to its fullest potential.

## Jean Pearmain - Myra Rosenfeld Volunteer Award



Pearmain has been involved with ALS since the 1980s when she began working as the nurse co-

ordinator of the Vancouver ALS Clinic. Since she retired she has volunteered for eight years, regularly giving 30 to 40 hours a week of her time. In his letter of nomination Andrew Eisen, MD, professor emeritus and lifetime director of ALS British Columbia, writes that Pearmain devoted, "all her

time and energy to help them and their families make the most of a terrible situation. She drove hours and miles to meet the needs of (the) ALS population in the regions, personally delivering equipment, advocating for them and simply being there."

The Myra Rosenfeld Volunteer Award recog-

nizes exemplary volunteer leadership. It is awarded for outstanding contribution to the advancement of the mission and goals of the ALS Society of Canada by a volunteer at the national/unit/chapter level. The award honors Myra Rosenfeld, a dedicated volunteer who died of ALS in 1990.

## Sidney Valo - Exceptional Fundraising Program Award



Valo used his business experience to become a top fundraiser with enormous success. In 2006 the Valo Fund raised more than \$52,000 for research,

and his WALK for ALS team raised more than \$29,000. "I made a conscious decision not to hide my condition, but rather to disclose it to one and all in an attempt to build awareness. I contacted any friends and acquaintances who I felt might support the Walk," says Valo. He is motivated to make a difference in the ALS communi-

ty because, "It's the one way to give this devastating disease a purpose."

The Exceptional Fundraising Program Award recognizes excellence in a fundraising initiative by an individual or a team. An exceptional program develops an innovative idea and attains or exceeds a fundraising goal.

The ALS Society of Canada is proud to recognize its award recipients for their efforts in support of the ALS community. If you know of someone who deserves to be recognized for their fundraising, awareness building or dedication to the ALS community, contact Enzo Raponi (er@als.ca) for a nomination package.

## Marcel Bertrand - Honorary Life Member Award



Diagnosed in 2000, Bertrand has never stopped helping others liv-

ing with ALS. Bertrand was a project manager for the Brummitt-Feasby ALS House in Winnipeg, the only palliative care house of its kind in North America. He was president of the ALS Society of Manitoba for six years, and dedicated to increasing

awareness of ALS at both the local and national levels. Bertrand was nominated by Lanny McInnes, a director of the ALS Society of Manitoba. In his nomination, McInnes writes that Bertrand is, "a champion for ALS and a tremendous example of

the courage people who live with this horrific disease display every day."

Bertrand passed away on July 29, 2007.

Honorary Life Members are named in recognition of extraordinary volunteer contributions to the ALS Society of Canada.

## Janice Davidson William Fraser Leadership Development Award



Davidson has been president of the North Central Island Chapter of the ALS Society of BC since she helped create it in 2001. In 2006 her guidance and energy ensured the success of the Oceanside

WALK for ALS and On A Roll for ALS. In nominating her for this award, Wendy Magee, executive director ALS Society of British Columbia, says, "In 2006 Jan chaired the Oceanside WALK for ALS using her leadership skills to create a sustainable committee to ensure the continuation of the Walk... [and] It was through her encouragement that

On A Roll for ALS will continue and is being expanded."

The William Fraser Leadership Development Award recognizes outstanding leadership development initiated and implemented by an individual, chapter or unit. This award honors William Fraser, a past president of ALS Society of Canada, who died in 2000.

## Elizabeth's Concert of Hope PEI correction

The Summerside, PEI leg of Elizabeth's Concert of Hope tour took place at the Harbourfront Jubilee Theatre, not Charlottetown as previously stated. The presenting sponsor was Rodd Hotels and Resorts. David Rodd's parents founded Rodd Hotel and Resorts in 1935 and Rodd expanded it into a leading chain in the hospitality industry in Atlantic Canada. Rodd passed away four weeks after the concert.

## 9th Annual Lorie Kane Charity Golf Classic

The 9th Annual Lorie Kane Charity Golf Classic was held September 13, 2007 at the Belvedere Golf Club in Charlottetown, PEI. Kane, Canada's most famous female golfer, donated \$50,000 in pro-

ceeds to the ALS Society of PEI in honor of her friend, David Rodd. Rodd led the development and expansion of Rodd Hotels and Resorts in Atlantic Canada before succumbing to ALS in 2006.



Pictured from left to right are John Cudmore, president and CEO of Rodd Hotels and Resorts, Marie Salamoun-Dunne, ALS PEI volunteer, and Lorie Kane. Photo courtesy of Charlottetown Guardian

## RESEARCH

## Progress in ALS detection



Janice Robertson, PhD.

**R**esearchers at the University of Toronto's faculty of medicine have developed the first antibody that detects the only known cause of ALS.

In approximately one to two per cent of ALS cases the cause is a mutation in the gene encoding the SOD1 enzyme. The newly developed antibody, named SEDI (SOD1-exposed-dimer-interface antibody), is the world's first tool for recognizing misfolded conformations of the enzyme SOD1.

This discovery opens up new avenues for research, including investigating the cause of this form of ALS, incidence, techniques for earlier diagnosis and immunization strategies. It also may have a diag-

nostic value for other types of ALS.

Janice Robertson, PhD, Canada Research Chair in the molecular mechanics of ALS at the

Centre for Research in

Neurodegenerative Diseases at U of T and one of the lead authors of the study, says, "This antibody will enable researchers to investigate whether misfolded SOD1 is involved in other forms of ALS." If SOD1 is involved "then the antibody could potentially be used in biomarker studies to facilitate earlier diagnosis of the disease."

The study's senior author, Avi Chakrabarty, PhD, professor of medical biophysics and biochemistry at U of T and senior scientist at the Ontario Cancer Institute, says, "The SEDI antibody also has utility in drug discovery efforts for identifying chemi-

cal chaperones that prevent or reduce misfolding of SOD1 in ALS."

"I don't believe we are overestimating the potential significance of this new research breakthrough. The attention of ALS research worldwide is now being focused on testing the hypothesis that either mutations or aging-related changes in the SOD1 molecule form the basis of a unified pathogenetic mechanism for most cases of ALS. The SEDI antibody will provide the first of a new generation of tools to begin testing this hypothesis," says Denise Figlewicz, ALS Canada's director of research.

This research was funded in part by ALS Canada's Neuromuscular Research Partnership.



Avi Chakrabarty, PhD.

## Bernice Ramsay ALS-MND Symposium Awards

**T**he ALS Society of Canada has established the Bernice Ramsay ALS-MND Symposium Awards to defray the travel and registration costs for Canadian ALS scientists, researchers and clinical professionals who attend the 18th International Symposium on ALS/MND December 1-3 in Toronto. One thousand dollars will be awarded to those who have had their papers or posters accepted by the symposium committee. This is the first time ALS Canada has offered this type of support to researchers and clinical professionals. A significant number of awards will be granted. These awards are made possible thanks to the generous bequest of Bernice Ramsay. The ALS/MND Symposium Awards represent the first in a series of new funding initiatives stemming from Ramsay's donation.

"The symposium is an opportunity to showcase the work of Canadian ALS researchers and for them to enter into discussions with other ALS researchers from around the world. Facilitating Canadian researchers' participation in this kind of event is an appropriate role for ALS Canada to play," says David Cameron, president and CEO.

"The symposium not only features presentations from scientists but also features sessions on clinical research - how to better diagnose, assess progression,

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## Guy Rouleau Wins Friesen Award



**Guy Rouleau, MD, PhD**

**G**uy Rouleau, a neurogeneticist at the University of Montreal, is the winner of the Henry G. Friesen Award. He was recognized for his extraordinary contribution to the human genome project, as well as his identification of genetic links to a number of major illnesses.

Rouleau and his team have worked hard to understand the genetic causes of many neurodegenerative and psychiatric diseases, including ALS. His work has resulted in the ability to identify disease-causing or predisposing genes.

There has been dramatic advancement in the area of

genome mapping, which will eventually make it possible to determine a person's predisposition to a variety of diseases. This will have many positive implications to the way people are diagnosed, treated and monitored.

Early detection of predisposition will lead to quicker diagnoses and ultimately the correct therapy. This will allow affected people to receive the appropriate treatment as soon as possible, prolonging and enhancing quality of life.

Rouleau believes that by 2020 all of us will be able to have our whole genome sequence done. Currently the human genome project is 98 per cent complete, and has identified 20,000

genes in human DNA. Rouleau believes there are as many as 30,000 genes.

At this time there are 2,000 genes linked to diseases, and it is likely that there are up to 10,000 more. Rouleau hopes to identify many of these over the next few years as technology advances.

This year's prize was awarded by the Canadian Society for Clinical Investigation (CSCI) and the Royal College of Physicians and Surgeons of Canada (RCPSC).

The prize includes a significant cash award, and supports annual fall lectures on topics related to the advancement of health research.



**More than 80 researchers and young investigators attended ALS Canada's 3rd annual research forum, held March 23-25 in Toronto.**

## Bernice Ramsay ALS-MND Symposium Awards

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assess quality of life and how to manage various types of symptoms. The symposium is a springboard for clinical professionals to take the latest information to their interdisciplinary team members which may lead to changes in clinical management practices, participation in further clinical study at their own centres, and ulti-

mately, better patient outcomes," says Jane McCarthy, director of services and education.

Three years ago, ALS Canada was invited to bid on being the host for the 2007 event. The last time the International Symposium was held in Canada was 1999 in Vancouver. We expect more than 1,000 delegates in Toronto.

## TECHNOLOGY

### A companion for independence

**F**or many people with ALS the first sign that something is wrong is loss of dexterity or difficulty with fine motor skills. As the disease progresses, more tasks become difficult. In recent years service dogs have become a tool and companion for people with ALS because they can help with various tasks such as carrying or fetching

objects and opening doors. They can also be trained to assist by pulling a wheelchair or bracing a person so they can independently transfer between their wheelchair and the bed, toilet, or other seat. Service dogs can be trained to bark for help, find or wake up a family member or caregiver, fetch respiratory equipment, and lie down on its partner's chest to

produce a cough. There are several organizations across Canada that train service dogs for people who have suffered strokes or have ALS, MS, muscular dystrophy, a spinal cord injury or cerebral palsy. For a list of organizations please visit <http://www.adionline.org/MemberDirectory/StatesandCountries100406.htm#Canada>.

### Dynavox Technologies makes speech-aid fun

**T**he new V and Vmax systems from Dynavox Technologies enable people with ALS who have lost the use of speech to communicate efficiently and effectively with their loved ones. The interactive system operates with a standard point-and-click mouse and features alphabets, words and sentences as well as

a series of customizable quick-reference menus for grouping commonly used phrases. The system also features a variety of language-use elements including age-appropriate settings and storytelling tools and connects to the internet, enabling the user to import images, sounds and videos from the internet, another com-

puter, or an external drive. The system runs with Windows XP, comes with remote technical support and operates with a large selection of natural voices to help the person with ALS customize their communication. A demo is available at: <http://www.dynavox-tech.com/dynavoxv/>.

### E-Triloquist technology helps people with ALS "Speak Easy"

**E**-triloquist, the personal communication aid software formerly known as SpeakEasy, has launched E-triloquist 5.7. The newest version's additional features provide a voice to those who have lost the ability to speak on their own.

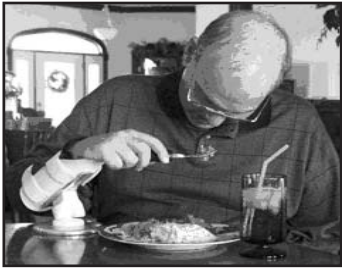
The technology, developed in 1995 by a son whose father was diagnosed with ALS, is a speaking device that can read typed words and phrases aloud in a human-sounding voice. The program works with any standard keyboard. For those in the later stages of ALS who are unable to type, the technology can also be paired with on-screen scanners, word predictors, single-switch input or other assistive input devices.

E-triloquist 5.7 includes audio features that allow users to record their own voices into the program. People with ALS who still have use of their voice can record words, phrases and sentences. The program stores these audio clips for use when speech cannot be produced.

E-triloquist technology is compatible with most PCs, comes with a comprehensive operations manual, and offers full support for Windows ME, Windows XP and Windows Vista operating systems. The technology is available free of charge and is downloadable through the E-triloquist web site, [www.etriloquist.com](http://www.etriloquist.com).



## The Arm Thing



**W**hen living with ALS, maintaining independence and dignity for as long as possible is the goal of many. Linda Edwards has found a way to help her husband and thousands of others living with ALS do this with her invention of The Arm Thing.

The device offers forearm

support, with an adjustable armrest sized to fit the user. The support rests on an aluminum channel and slide, which adjusts to the height of the forearm. The arm piece is connected to the aluminum base with a ball-and-socket connection, allowing a 360-degree rotation. The arm piece has a glide to adjust the angle for different table heights. The user's arm is secured to the device using two nylon straps with hook-and-loop attachments. The base's non-skid surface ensures the user's arm will not slip.

"It's changed Ron's life, and I want to be able to

help others with ALS," Linda explains.

The Edwards' came up with a few professional names, but "nobody liked them, and everybody kept calling it the arm thing."

Ron says, "It allows me to go out and be with my friends and family. Somebody has to put my arm in the device, but everybody's used to it. It's about having a life and maintaining my dignity."

The standard arm piece costs \$449 U.S. and the extended wrist support model that reaches the palm of the hand is \$479

U.S. For more information visit [www.mtedevices.com/](http://www.mtedevices.com/)

*Excerpted from an article in the MDA/ALS Newsmagazine, with permission of the Muscular Dystrophy Association of the U.S.*



Ron Edwards uses the Arm Thing for tasks requiring support for weakened hands and arms.

## Infoway creates web portal to support caregivers

**A** new web portal that will support Canadian caregivers is set to launch in June 2008.

This portal will equip caregivers with information on providing care, financial advice and respite supports. The portal will also include a discussion

board and a Caregiver Electronic Record (CER) which will allow caregivers to communicate with each other and community care sectors.

The bilingual web portal will enhance the quality of care people will receive in their homes as well as reduce visits

to clinics, physician offices and emergency rooms.

The project is supported by a \$1 million investment from Canada Health Infoway, and is designed to help 3,000,000 Canadians better care for their loved ones.

## MarVision device helps families "talk to mom"

**W**hen Marlene Miller was diagnosed with ALS in 1997, her family was devastated. As the disease progressed, Miller lost the ability to communicate with her loved ones, making even simple family gatherings seem tedious and overwhelming.

Frustrated at the inability to communicate with his mother, Miller's son,

Roger Kearns took it upon himself to locate a device that would let the family once again "talk to mom". Kearns's solution became the MarVision Device and Method.

The system does not rely on computer technology or cumbersome machinery, opting instead for only a small, lightweight class II laser pointer and a booklet. The system oper-

ates on two AAA batteries, used to power the laser. The non-verbal communication method works by attaching the laser pointer to one's eyeglasses, hat, finger, or arms, allowing for people in various stages of ALS to use the device in the way most comfortable to them.

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## End-of-Life Preferences

**D**espite having a significantly worse survival outcome, cancer patients are less likely than patients with ALS to have evidence of an out-patient discussion about end-of-life treatment preferences, New York researchers report.

Investigation reviewed the out-patient charts of 60 patients with advanced cancer and an expected two-year survival of less than 50 per cent, and 32 recently diagnosed ALS patients.

At a three-month follow-up, ALS patients were significantly more likely to have documented discussion of wishes regarding ventilator support (35 per cent vs 0 per cent), artificial nutrition and hydration (40 per cent vs 0 per cent), resuscitation (29 per cent vs 0 per cent), and hospice care (25 per cent vs 5 per cent). Ninety-one per cent of ALS patients were alive at six months, compared with 62 per cent of cancer patients. At two years, 63 per cent of ALS

patients were alive, while only 23 per cent of cancer patients were still living.

"Patients with advanced cancer need information about treatment options if they are to make informed decisions about end-of-life care," note the authors. Otherwise, these patients might be "forced to confront these difficult issues only when hospitalized and close to death."

Source: "Discussing End-of-Life Treatment Options: Advanced Cancer vs. Amyotrophic Lateral Sclerosis," Abstract, American Society of Clinical Oncology Annual Meeting, May 2005.

Astrow A.B., Sood J.R., et al; St. Vincent's Hospital and Medical Center and New York Medical College, New York City.

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## MarVision device helps families "talk to mom"

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The laser can then be used to point out various key words, phrases and pictorial representations contained in the accompanying booklet. The booklet also includes an alphabet chart that enables people using the system to spell out words and instructions as required.

The system comes with a portable music stand that keeps the booklet open to the desired page, and allows for it to be placed at a convenient distance from the laser pointer.

The portable system costs \$225 U.S. For more information please visit: [www.marvision.com](http://www.marvision.com).

## ALS

So this is how my story ends,  
Not when I'm young, surrounded by friends,  
Not in an accident or a fall in the night,  
Nor full of energy, burning bright,  
Not in a brawl or a drunken rage,  
But from a disease slowly stage by stage,

I see the pity in their eyes,  
Thinking thank God it's you, not I,  
With each dawning of a new day,  
My choices have further withered away,

Now I sit and listen while people prattle on,  
About a world that I once belonged,  
For I exist in just two rooms,  
But I can see my fate, my impending doom,

That soon my room will just be one,  
Hidden from the warming sun,  
With a little stone far above my head,  
Declaring that I lived though now I'm dead,

That I loved and laughed and sang the songs,  
But now I sit and watch for my voice is gone,  
Waiting for the final toll, the final chime,  
That marks the end of my time,

For ALS is a relentless foe,  
That sinks its teeth in and won't let go  
Ripping at my fabric my very soul  
For suffering not death is its goal

By: Peter Wilton  
(his mother died of ALS last fall)



## SEED Grants

The ALS Society of Canada is pleased to announce the 2007 Service and Education Enhancement and Development (SEED) Grant Program award recipients. The purpose of the program is to provide financial assistance to provincial ALS Societies wishing to further develop their service delivery capacity or outreach to improve quality of life for as many people living with ALS as possible. The total budget for the SEED Grant Program in 2007 is \$100,000.

David Cameron, president & CEO of the ALS Society of Canada says, "The support the SEED program provides to the provincial ALS Societies allows them to improve the quantity and quality of services offered to people living with ALS. We are extremely pleased that this year we were able to fund so many diverse programs across the country."

The application evaluation process involved an impartial review committee which used an objective scoring system to measure the quality of the information provided in the application, the relevance to the program objectives and the potential for broader application. Once group consensus was achieved, the funding recommendations were submitted to the ALS Canada executive committee for approval.

The successful applicants are as follows:

### Mobile ALS Clinic

#### ALS Society of British Columbia

The ALS Society of BC conducted a client survey that showed medical care is the main priority. The survey also showed that the "need to see ALS centre staff close to home" was rated "very important" by 82 per cent of patients and 75 per cent of caregivers. The mobile clinic concept allows for high-quality regionally based ALS assessment and follow-up by the GF Strong ALS team while reducing the travel and trans-

portation challenges for people living with ALS outside the Vancouver area. The proposed project is to pilot test the mobile clinic in Nanaimo and Kelowna. The initiative will be evaluated to determine program continuation.

### Province Wide Client Service Initiative

#### ALS Society of Manitoba

There is a need in Manitoba to build capacity to enable expanding client access to the equipment program, Volunteer Family Advocate Friend service, and children's programs both inside and outside of Winnipeg. This initiative aims to increase service equity across the province to meet identified needs. To accomplish this, a volunteer/event coordinator will recruit, train and place visiting Family Advocate Friend volunteers and assist in strategies designed to develop financial capacity to increase equipment inventory to meet client needs currently not being met.

### Atlantic Region ALS Conference

#### ALS Society of Nova Scotia

The four Atlantic provinces have limited populations and resources, making it a challenge to independently develop capacity and provide adequate services. The ALS Society of Nova Scotia will implement a conference to bring together people with ALS, volunteers, health-care providers, and society staff within the region to identify areas of mutual concern and investigate potential collaborations to better serve people with ALS in the region.

### Volunteer Training, Support and Succession Planning Pilot Program

#### ALS Society of Ontario

One regional manager is currently supporting the entire Greater Toronto Area (GTA) but more people are required to adequately meet client needs in this densely populated geographic region. This initiative aims to enable the society

to support and sustain two volunteer chapters in the GTA (Brampton and North York) that are currently experiencing difficulty in recruiting and sustaining leadership. Results of this pilot will allow the society to apply what it learns to improve the critical issue of volunteer instability across the province.

### Manual and Training for Professional and Family Caregivers

#### ALS Society of Quebec

The ALS Society of Quebec has received several requests for caregiver training from both clients and professional caregiver agencies. Based on the results of the 2005 SEED program initiated by the ALS Society of Alberta (*Personal Care Attendant Training*) the ALS Society of Quebec proposes to modify the program for the Quebec caregiver audience and implement a training program in key regions to coincide with "En Route" dates, scheduled for March to May 2008. The program will target private home care companies, home care, nursing homes and family caregivers.

### Traveling ALS Support

#### ALS Society of Saskatchewan

Approximately 80 per cent of people in Saskatchewan living with ALS live outside Regina and do not benefit from the available support there. The ALS Society of Saskatchewan plans to travel to clients to provide in-home visits or facilitate client transportation to access support in Regina. The initiative includes recruiting three board member volunteers to co-ordinate and provide client visits outside the greater Regina area over the implementation period. Client feedback will be collected to evaluate the degree to which the traveling program increases membership of clients outside Regina and impacts their perceptions about the role of the society.

# YOU CAN

## Provide hope and help to people with ALS.

You can help fund urgently needed research into finding an effective treatment and a cure for ALS and support services to those with ALS.

Please consider a planned gift to the ALS Society of Canada.

### Planned Giving is:

- A gift or bequest made after careful consideration through your financial or estate plan
- A gift that requires some type of legal documentation, i.e., will or a life insurance policy
- A gift that may have tax advantages under current laws
- A gift that is arranged now to provide funds at some time in the future

Making a planned gift to the ALS Society of Canada is easier than you think.

Please contact **1-800-267-4ALS** ext. 228 for assistance.

### Contact ALS • 1-800-267-4257

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