

# Coast to Coast



| Winter 2006

## ALS Print Ads

**B**BDO Canada, the advertising agency that created our PSA campaign, "What would you do while you still could?" has also designed two print ads which appeared in newspapers, subway stations and buses across the country in June for ALS Awareness Month. The print ads worked as the educational piece of the campaign, allowing more information to be shared about what ALS is and what it does. Keeping with the "What would you do while you still could?" theme, the ads read: People with ALS often lose the use of their arms. Which is why we're asking you to write the cheques.

The second ad states: It's ironic that a disease that makes you want to pound your fists in anger leaves you unable to do so. The two ads capture the tremendous effects of the disease with bold letters and photos of the hands of people who are living with ALS, reflecting the urgency to find a possible treatment or cure. They were created to build awareness of ALS and the ALS Society's efforts to support research towards a cure for this devastating disease. The print ads have run across Canada in *The National Post*, *The Montreal Gazette*, *La Presse* and the *Vancouver Province* newspapers.

<b>The ads ran in the following cities:</b>	Belleville Cobourg-Port Hope Saint John Fredericton Sydney Red Deer Regina Saskatoon Toronto subway	St. Catharines-Welland St. Thomas Stratford Woodstock North Bay Ottawa Sudbury Thunder Bay	Halifax Moncton St. John's Charlottetown Brandon Calgary Edmonton Lethbridge Medicine Hat
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**IT'S IRONIC THAT A DISEASE THAT MAKES YOU WANT TO POUND YOUR FISTS IN ANGER LEAVES YOU UNABLE TO DO SO.**

To see this important public information on your newspaper, please check with the publisher of the issue of your local paper, or call, fax, e-mail, or visit the website: www.als.ca. Please support the work of ALS Canada and help us find a cure for this disease. Your cheque will help us do this.

Thousands of people in Canada are living with ALS. Please contact ALS Canada at the ALS Society of Canada's National Office, 2000 St. Lawrence Blvd., Suite 100, Ottawa, Ontario K1M 1S1. We will provide you with more information. Tel: 1-800-387-2222.

**ALS PLEASE GIVE**  
www.als.ca

**PEOPLE WITH ALS OFTEN LOSE THE USE OF THEIR ARMS IN THE FIRST TWO YEARS OF THE DISEASE. WHICH IS WHY WE'RE ASKING YOU TO WRITE THE CHEQUES.**

It's ironic that a disease that makes you want to pound your fists in anger leaves you unable to do so. The two ads capture the tremendous effects of the disease with bold letters and photos of the hands of people who are living with ALS, reflecting the urgency to find a possible treatment or cure. They were created to build awareness of ALS and the ALS Society's efforts to support research towards a cure for this devastating disease. The print ads have run across Canada in The National Post, The Montreal Gazette, La Presse and the Vancouver Province newspapers.

Thousands of people in Canada are living with ALS. Please contact ALS Canada at the ALS Society of Canada's National Office, 2000 St. Lawrence Blvd., Suite 100, Ottawa, Ontario K1M 1S1. We will provide you with more information. Tel: 1-800-387-2222.

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## The John's Journey Campaign

The MND Association of England, Wales and Northern Ireland have launched a web site for their public awareness campaign, *John's Journey*.

The campaign aims to raise the profile of motor neuron disease (MND) through the story of one man's courageous approach to life with this devastating condition.

John Bell, 31, from Sheffield, U.K., was diagnosed four years ago, but has refused to let MND stop him from becoming a husband to his childhood sweetheart Charlotte, or a father to his two young sons Gabriel, three, and Samuel, one.

Despite his failing health, Bell has volunteered to be the subject of an advertising campaign on the London underground, which launched at two stations on October 24. Commuters passing through Euston and King's Cross - two of London's busiest underground stations - will follow his progress as MND takes its toll.

Bell has devoted his remaining months to raising awareness of MND, which affects 5,000 people in the U.K. For the past two years Bell has allowed TV cameras to film his gradual deterioration, and the impact of MND on him and his family. The result was a two-part ITV documentary screened earlier this month on ITV Yorkshire.

Visit [www.johnsjourney.org](http://www.johnsjourney.org) to follow Bell story of living with ALS/MND and leave a message for Bell and his family.

To view the campaign visit <http://johnsjourney.org/campaign.php>

## ALS Society of Canada releases *A Guide to ALS Care for Primary Care Physicians*

The ALS Society of Canada is pleased to introduce - *A Guide to ALS Care for the Primary Care Physician*. The purpose of the newly published electronic guide, available on CD-ROM and as a PDF document on [www.als.ca](http://www.als.ca), is to inform primary care providers (often general and family medicine practitioners) about ALS and how to recognize and manage the symptoms to promote timely diagnosis, intervention, and optimal quality of life throughout the continuum of care.

Jane McCarthy, director of services and education, says that "often a person with symptoms of ALS may not get as timely a referral to an ALS specialist for diagnosis and care because the primary care physician or the referring neurologist may not be familiar with ALS. ALS is an extremely complex, progressive neurodegenerative disease. It needs to be well understood by the primary care physicians of these patients to ensure optimal ongoing management and care co-ordination with community supports and, ideally, an ALS specialty team. Persons with ALS and their family caregivers benefit greatly when their primary care physician becomes a knowledgeable, pro-active member of their ALS health-care team."

The *Guide* contains numerous sections on major symptoms and clinical management issues that can arise in people living with ALS, from the point of diagnosis to the end-of-life stage. The guide also contains background information on ALS, research theories, specialized equipment for activities of daily living, recommended additional reading, internet resources, and contact information for the ALS Society, its provincial affiliates, and ALS clinics and rehabilitation centres throughout Canada.

### Distribution Plan

Primary care doctors who have newly diagnosed patients with ALS will be targeted through ALS clinics and centres and provincial ALS Societies. This approach will ensure that as many primary care doctors as possible who have ALS patients will receive the *Guide* early in the disease process enabling them to best promote quality of care.

Each time a person is diagnosed with ALS, the ALS Clinic/Centre co-ordinator will introduce the CD-ROM to the person living with ALS and allow them to choose whether to take it to their family physician, or have the clinic forward it to the physician on their behalf.

This distribution method will facilitate communication and co-ordination between the ALS specialty team and the primary care physician. Provincial societies will also provide the CD-ROM to those with ALS to give to their family doctors.

To broaden the distribution and promote the *Guide* to a wider clinical audience, ALS Canada participated as a partnering sponsor at the 2005 Family Medicine Forum, the annual conference of the College of Family Physicians of Canada (December 8-11 in Vancouver, B.C.) and distributed CD-ROMs to 1,400 delegates at the meeting. Presence at this event also resulted in raising the profile of ALS and the Society to the primary care sector and to other corporate sponsors at the meeting. Last year, this meeting was rated as one of the 50 fastest growing meetings in North America.

Press releases were sent to the media (health reporters) and targeted health-care publications and associations to promote the web-based version of the *Guide* and the ALS Society.



## Report from the President and National Executive Director

David Cameron has been asked to accept a nomination to the Board of Directors of the International Alliance of ALS/MND Association. ALS Canada is a founding member of the International Alliance. Over the past year we have been forwarding to their offices our communications materials, PSA information, and research updates and they have then been sent around the world to the 35-member organizations. The awareness of ALS Canada and its activities is high in the international ALS community as a consequence. By accepting a position on the Board, ALS Canada will be better able to influence the direction of the International Alliance, and it elevates our credibility.

David was invited to present at the International meeting details on the Public Service Awards (PSAs) program as well as our new **WALK for ALS** and the **Hike 4 ALS**.

The Research Policy Committee has been re-populated this fall and its members consist of Doctors Jean-Pierre Julien,

Michael Strong, Heather Durham, Elizabeth Meiring, Charles Krieger, Janice Robertson and Wendy Johnston.

At the November Board of Directors' meeting approval was given for the hiring, in 2006, of a Director of Research who will work with the Research Policy Committee to determine the most effective use of the research funds available to ALS Canada.

The Tim E Noël Endowment Fund, a creation of the "Friends of Tim Noël," and designated to be used for research, has decided to use the available interest from the endowment to fund a post-doctoral fellowship in ALS research, for up to three years. The opportunity will be made available through a partnership with CIHR and is valued at up to \$75,000 annually. With that dollar amount the quality of the applicants for the position will be assured. It will encourage a bright young scientist to become interested in the field of ALS.

2005 heralded the first year of the new **WALK for ALS** pro-



Sean McConkey  
President



David Cameron  
National  
Executive Director

gram which built on our previous experience. We had 63 Walk sites and more than 13,000 participants. The total raised was in excess of \$1.7 million.

The first year of our new concept of the **Hike 4 ALS** is complete and we had four Hike sites across the country - Kortright Centre for Conservation, Vaughan, Ontario; Crystal Crescent Beach Provincial Park, Sambro, Nova Scotia; Panorama Park, Vancouver, British Columbia; and, Jumpingpound Loop Trail, Kananaskis, Alberta.

We found that the audience for a hike experience differs from those who participate in the Walk program and the two events do not compete for participants. The **Hike 4 ALS** raised more than \$45,000 and was a modest success. We anticipate an expansion of locations and revenue in 2006.

Other events that took place in Victoria during ALS Awareness month were, "On a Roll for ALS," which ran from June 2 - 10, and the Victoria Chapter's involvement in the Victoria International Track Classic. The city also held an ALS Corporate Mile Relay at the track meet, raising in excess of \$3,000, with more than 3,000 spectators attending.

handing out blue cornflowers in exchange for donations. Thousands of the silk cornflowers were given to all those who made a donation. "The ongoing success of this annual event can be accredited to the large number of volunteers who give their time and energy to this very important cause," says ALS volunteer and president of the Victoria Chapter John Braun.

## Picton - Masons Present \$74,000 to ALS Society

The Masons of Prince Edward District presented a cheque for \$74,000 to the ALS Society of Ontario - Quinte Chapter. A presentation was made at the Picton Lodge on September 18. Attending dignitaries included MP Daryl Kramp, MPP Ernie Parsons, Mayor Leo Finnegan and Hastings County Warden Charles Mullett. Bill Goodfellow from Brighton and John Rymes, who have ALS, attended the presentation with their families. The money was raised by raffling off an all-terrain vehicle with trailer. Other prizes included a weekend in the Niagara region.

There are approximately 64,000 Masons in Ontario with 630 lodges in 46 districts. There are 14 lodges in the Prince Edward district. In Ontario donations from the fraternity are in excess of \$3-million annually and each district has a particular fundraising project and this year the Prince Edward District chose ALS.

Cindy Rymes said that the ALS Society brings her husband comfort, hope and belonging. Its exceptional equipment program brings comfort and its excellent research brings hope that some day there will be cure.

Susan Graham Walker, executive director of ALS Ontario said the Quinte Chapter is establishing a unique transportation program in Ontario which she says may well provide a model for use across the province. Details of the exciting new program will be announced shortly.

## Victoria's One-Day Donation Drive Raises more than \$25,000 for ALS Research

This past June, The ALS Society of BC's Victoria Chapter held its annual One-Day Donation Drive to support ALS research and client support services. This year's effort was a great success, raising \$25,000.

On June 4, from 10:00 a.m. - 6:00 p.m., more than 300 volunteers at 35 different locations across the city of Victoria were

## BBDO Canada Creates Award Winning Public Service Announcements (PSAs)

**B**BD O Canada, the advertising agency that created our PSA campaign, "What would you do while you still could?" has received numerous awards for the "Running" and "Hugging" PSAs. The PSAs can be viewed from our web site at [www.als.ca](http://www.als.ca)

The agency was recently recognized with the following awards:

### Cannes International Advertising Festival

The PSA "Hugging" has been awarded a Bronze Lion from the Cannes International Advertising Festival. This prestigious event, also known as the "Olympics" of advertising, was held from June 19-25 in Cannes, France and drew an audience of 8,000 people from more than 75 countries. Ten Canadian agencies were among those honored at 52nd annual festival with awards presented in 10 advertising categories, including film, press, outdoor and cyber. The festival offers experts from the advertising world the opportunity to promote themselves by showing their best and most original work in this unique international event. Entries are judged by an international jury, and the shortlist of approximately 450 films is decided by the first voting. A computerized voting system selects the highest marks given in each category, and further

voting establishes the ranking in each category, which is the basis for the Juries discussions and the awarding of Gold, Silver, and Bronze Lions. The film Grand Prix is then selected from all the Gold Lion Entries. Charities and public service categories are excluded from winning the Grand Prix.

### The Bessies

"Hugging" received finalist recognition (single) on June 9th at the Bessies. The Bessies is an annual TV commercial competition organized by the Television Bureau of Canada in conjunction with the Broadcast Executive Society. Entries are accepted from individuals or groups engaged in creating or producing Canadian television commercials.

### Marketing Awards

"Hugging" and "Running" received a bronze award at the 2005 Marketing Awards on March 31st. The category was Public Service TV and Radio campaign. The Marketing Awards, which trace back 83 years, are Canada's leading national awards recognizing excellence in advertising creative. The 150-member jury examined 2,033 entries and gave out 158 gold, silver, bronze, and certificate prizes.

### Canadian Marketing Awards

BBDO Canada received a Silver Award at

the 2005 Canadian Marketing Awards on November 25th. The agency received the award in the Charity/Pro Bono category.

For the fifth consecutive year, the Canadian Marketing Association has broken the record for the number of entries in the CMA Awards competition. A total of 696 submissions were received in the 2005 competition, 31 more than in 2004.

Winning a CMA Award has been a symbol of excellence for 36 years, making this the pre-eminent award honoring marketing campaigns that achieve solid business results. The largest marketing awards celebration and longest-running event of its kind in Canada, the CMA Awards bring together all marketing disciplines, channels and technologies to celebrate the year's best marketing achievement.

### PSA Played in Famous Players Theatres across Canada

Our 30-second "Hugging" spot (English and French) was shown in Famous Players theatres across the country. The spot ran from April 8 - 29 on 591 screens in 47 different locations and aired approximately 156,024 times, with 1.4 million guests. BBDO Canada arranged for the PSAs to run (at no charge to ALS Canada) in the theatres. The total gross dollar value for the spots was \$50,250.

## ALS March of Faces

ALS March of Faces was launched in Canada in 2002 and is an awareness tool for local ALS Society activities. Each ALS March of Faces Banner contains 20 color portraits of people living with, or who have passed away, from ALS. ALS March of Faces was started by Kyle Hahn in the U.S. George Goodwin, Canadian program co-ordinator of ALS March of Faces, became friends with Hahn and his caregiver, Terry Frank, and they began discussing bringing the program to Canada. Since then the project has taken off with the program now being implemented in Australia and New Zealand. Currently,

there are more than 600 participants from across Canada with 59 printed banners. All provinces have at least one banner, and this project is one of the best awareness tools that the ALS Society has to offer. The ALS March of Faces is a unique approach to generating awareness by putting a picture to a name and a name to ALS.

"It is very easy to say that 60 people are living with or have died from ALS in a certain community but to show them on a banner is another thing altogether. People then begin to recognize these people as neighbors or past friends and then the

penny drops as to just how devastating and indiscriminate this disease can be," says Goodwin.

He has been actively involved with the project from the very beginning; he sits on the U.S. board of directors of the ALS March of Faces and is now the first vice-president of the ALS March of Faces while continuing to co-ordinate the Canadian ALS March of Faces. Goodwin also operates a web site - [www.alsindependence.com](http://www.alsindependence.com) - where the ALS March of Faces is on display by province as well

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## 'I am a walrus'

# How does a man facing a death sentence voice the humour that can be a part of human tragedy, especially when he is the victim in the unfolding drama?

By Keith Kress  
Thursday, July 7, 2005  
*The Globe and Mail*

I never understood what John Lennon was singing about until Ralph, my brother-in-law, muttered these words as he was dragged unceremoniously across the white sandy beach where no wheelchair could go and into the warm waters of the Caribbean where he could float effortlessly, momentarily free.

A short year earlier Ralph, a buff, muscular 6-foot-4 teacher, hockey player, adventurer, cyclist and all-round outdoorsman, had raced his wife Zora across a similar stretch of sand, diving headlong into a surging wave, revealing in the moment. What a difference a year makes.

What went wrong? Now his legs were dead limbs that ignored his brain's commands, his hands and arms playing catch-up with the useless lower extremities. Soon he would not be able to feed himself but would rely on caregivers to sustain him as he inched toward the inevitable conclusion that accompanies those afflicted with amyotrophic lateral sclerosis also known ALS or Lou Gehrig's Disease.

Ralph is gone now but I often think of his re-creation of that moment on the beach and the light in his eyes as he uttered the walrus analogy. How does a man facing a death sentence have the ability to see and voice the humour that can be a part of human tragedy, especially when he is the victim in the unfolding drama? That was Ralph: He could still make light of his predicament (although he never took it lightly). He had a way of minimizing the obvious, creating an accepting comfort-level for those in his presence, for it is not always easy to "enjoy" the company of someone who is in the process of dying. Ralph made it happen. We his family, his myr-

riad of friends and all who came into contact with him should be better for the experience.

We all know we are going to die, we just don't know how or when; it's something we'll do some time; we'll get around to it, you know, but not now. Ralph knew. Not the exact day perhaps but he knew and he determined that he would take the advice of the poets and live life until he died.

Knowing that you are going to die, knowing that you have but a short period to remain with your wife, children, family and friends, changes all the relationship parameters of daily life. As Ralph prepared to leave us, he drew us to him, motivating each of us on a personal level. As he brought out the best in himself for the most part he brought out the best in everyone who touched him.

Movement had always been of paramount importance, a virtual necessity to Ralph's mental as well as his physical well-being and as his freedom was curtailed he adapted, never remaining in one spot longer than necessary. From canes to motorized scooter to the industrial-sized Cadillac of power chairs with all the bells and whistles Ralph was out and about whenever he could be.

Time was precious and every day required greater preparation time before he could get rolling -- but get rolling he did. He met with his hockey buds, the friends from his fitness club, teachers from past and present, family. Schedules were written and re-worked, everyone accommodating and participating.

It was summer finally and we hit the patios in Toronto: North Yonge, the Danforth, Little Italy. He sipped beer through a straw, someone holding the glass, and he patiently allowed himself to be fed chicken wings or scallops in sauce. We, who were healthy and had never found ourselves catering to a person with dwindling capabilities, were humbled by these experiences and ultimately were hon-

oured to take part.

As Ralph's abilities failed him he allowed us to counterbalance and I like to think that we were better for it. It wasn't a fair trade but Ralph didn't keep score. He was busy, active literally until the day before his passing. We had a dinner planned but he couldn't make it at the last moment as his lungs were failing unexpectedly and he was rushed to hospital and admitted into critical care. He wasn't going to recover.

News was passed and dozens of people came to the waiting area outside the secure doors limiting entry. As the day passed, more than 100 came to be near, to open their hearts to Ralph, his wife, his children, his parents. Ralph saw them all, no one was turned away and while initially the hospital rules were obeyed (two visitors at a time), eventually a blind-eye was turned and his cubicle was filled to capacity. He could not speak behind the mask, sophisticated machine breathing on his behalf, but his eyes were bright and knowing of all who came to offer words and perhaps prayers. He waited for a sister who caught a plane and arrived in time to say hello and then goodbye.

He was serenaded and held and went to sleep with 32 of us missing him already and wishing him a good voyage.

A brief clip that remains with me: Ralph, looking cool and collected one evening early on in the disease's progress, surrounded by a table of friends (who do not see his steely determination), stood up, threw away his canes, and announced what we were all praying to hear: "Just kidding guys, I was just kidding."

*This article is reprinted with permission of the author Keith Kress who lives in Toronto.*

## Coffee Companies Support ALS Societies

**P**istol & Barnes, a local B.C. coffee company is lending its support to those living with ALS in the province. The company will be donating 10 per cent of "in-room" coffee packet sales, as well as \$5 from every 1lb coffee bag to the ALS Society of British Columbia.

Pistol & Barnes imports and distributes coffee under the Farmer First banner and offers 13 different blends as well as hot chocolate and teas. The coffee is shade-grown in a sustainable fashion and bird-friendly. Farmer First coffees are purchased from long-established co-operatives, family farms, and ethical importers. Many of these coffees are purchased from co-operatives listed on the Fair Trade Labeling Organization Register.

Pistol & Barnes purchases from coffee farmers for fair prices, enabling the company to make more money for its crop than it would from selling the same coffee to corporate coffee giants. P&B holds to the principles of social responsibility, dedicating themselves to the improvement of the well-being of people in the Lower Mainland and around the

world. To learn more about P&B go to [www.pistolandbarnes.com](http://www.pistolandbarnes.com)

### ALS Society of Ontario

And in Ontario, The Creemore Coffee Company is selling bags of coffee for \$9.95 at Creemore Farmer's Market in Creemore, Ontario. Forty per cent of the proceeds raised went towards the **Barrie WALK for ALS**.

Sandra Lackie, an ALS Society of Ontario volunteer and a rehabilitation consultant, came up with the idea. The coffee is sold in her community - Creemore, Ontario, a population of 1,317. She felt it would be a good fit because it's a Fair Trade coffee with the proceeds going to help people living with ALS. When Lackie approached the owner of The Creemore Coffee Company, Dave Nesbitt, he was happy to become involved. Currently the coffee is only being sold in the summer, but Lackie has already spoken to the owner about future opportunities to sell the coffee in support of people living with ALS.

The Creemore Coffee Company is a distrib-

utor of Fair Trade certified coffee and hot chocolate. The primary market focus is gift stores, gift baskets, gift basket providers, gourmet cafes and church, social and environmental organizations involved in fundraising. They also sell directly to consumers not serviced by one of their retailers through its website at [www.creemorecoffee.com](http://www.creemorecoffee.com).



## June is ALS Awareness Month

**T**housands of ALS staff, board members and volunteers across Canada dedicated their time and efforts to raise money for ALS research and client support services in June for ALS Awareness Month. They handed out cornflowers, spoke to the public and provided information to help ensure that Canadians are made aware of ALS.

The Blue Cornflower, also known as the Bachelor's Button, was chosen as the national symbol of hope for ALS because, despite its fragile appearance, it is a hardy, long-lasting wildflower found throughout Canada. Like the cornflower, people with ALS show remarkable strength in coping with this devastating disease. As the Blue Cornflower is planted, awareness of ALS grows along with it across the country.

In addition, a communications manual (English and French) was prepared for ALS Awareness Month which was distributed to

the provincial units to assist with getting our key messages out to the public. Across the country, ALS Societies held walks, runs, and other activities to raise awareness of ALS. David Tilson, MP led the way by declaring June as ALS Awareness Month in the House of Commons. And, Bryon Wilfert, MP published a newsletter in June about ALS.

ALS Awareness Month was publicized by the following health-care organizations and companies:

- Ontario Society of Occupational Therapists in its May monthly broadcast email update to members;
- *Healthy Living Magazine* series (Wal-Mart Canada Corp. Pharmacy department);
- Ontario Health Promotion E-Mail Bulletin (June 2005);
- Canadian Hospice Palliative Care Association web site;
- *The EnableLinker* - the E-zine linking you to Canada's disability community (June 2005).



*Cornflower campaign during ALS Awareness Month - two Ontario ALS Society volunteers sold cornflower plants during ALS Awareness month at the Kingston Market. Left to right Terry Vincent and Celine Zakos. Vincent's husband Harold passed away two years ago from ALS. Zakos is Harold's niece.*



**David Tilson, MP**  
**Dufferin-Caledon**

For Immediate Release

## PressRelease

June 1, 2005

### TILSON RECOGNIZES ALS MONTH IN HOUSE

**PARLIAMENT HILL** – David Tilson, MP for Dufferin-Caledon made a statement in the House of Commons today which gave recognition to the month of June as ALS month. After introducing a private members bill that would officially designate June, across Canada, as ALS month, Mr. Tilson encouraged his colleagues to support ALS research by purchasing a cornflower this month.

Approximately 2,000 Canadians currently live with ALS. Two or three Canadians lose their battle to this devastating disease every day. With improved knowledge about ALS, healthcare providers and families can help those living with this disease live life more fully.

The ALS Society of Canada recognizes the involvement of volunteers at all levels of the organization as a vital component to achieving its mission of helping people living with ALS and raising funds for ALS research.

Throughout the month of June ALS societies across Canada will be raising money for research through a variety of ways. One of which is through the sale of cornflowers. Show your support for ALS research, buy a cornflower.



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## ALS March of Faces

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as on his "In Memoriam" pages for those who have lost their battle with ALS. Banners are displayed at various community events such as the **WALK for ALS**. Canadians living with ALS and surviving family members of people who had ALS are encouraged to add a portrait to the March of Faces banners. There is always a great deal of public interest when and where the banners are displayed, thereby raising awareness of the disease.

"With awareness comes the money for research, with research we will find the treatment or cure. They go hand in hand and, someday, we will ultimately find the answer," says Goodwin.

For more information about the ALS March of Faces please visit [www.alsindependence.com](http://www.alsindependence.com) or email Goodwin at [george.goodwin@sympatico.ca](mailto:george.goodwin@sympatico.ca)

## Elizabeth's Concert of Hope

ELIZABETH'S



CONCERT OF  
HOPE



"Music will always be with us. It is a universal language that carries the message of joy, hope and humanity from the past, through the present, and into the future."

Elizabeth Grandbois

After being diagnosed in 1997 with ALS, Elizabeth Grandbois, a nurse, wife and mother, vowed to find a way to increase public awareness and understanding of ALS. With unwavering determination, a strong sense of urgency, and the full support of her family and friends, her dream became a reality on February 2, 2001 with the creation of the first benefit concert.

Elizabeth's Concert of Hope is an established annual musical extravaganza that has galvanized a community and raised \$1.6 million.

"This year our goal is to reach a cumulative total of two million dollars. The concert for 2006 is the finale for Hamilton. It marks the end of this dream and the beginning of the next; a Canadian tour of Elizabeth's Concert of Hope," says Grandbois.

Tickets for the sixth and final concert are now available from the Dofasco Centre for the Arts in Hamilton, 1-800-456-PLAY. For more information about the concert go to [www.elizabethsconcertofhope.com](http://www.elizabethsconcertofhope.com)

Due to the tremendous success of these events, Grandbois is in the process of organizing a two to three month Canadian tour to commence next fall as a follow-up to the final Hamilton event. With the support of provincial ALS societies, the goal is to host a concert in every province in hopes of sharing the celebration with fellow Canadians and bringing national focus to this devastating illness. The concerts have proven to be a positive and uplifting way to garner recognition of ALS.

If you are interested in supporting this goodwill endeavour please contact your local ALS Society.



**W**ALK for ALS is the signature fundraising event of the ALS Society of Canada run in partnership with provincial ALS Societies across the country. The Walk is designed to raise money to support those living with this devastating disease and to raise awareness and funds for ALS research. In 2005, 63 walks raised more than \$1.7 million. Forty per cent of the proceeds will support the ALS

research program and the other 60 per cent provides local services for those affected by ALS.

The 2005 **WALK for ALS** was once again supported by McDonald's Restaurants of Canada, national presenting sponsor, and Canon Canada, national gold sponsor.

Walks took place across Canada during the spring and fall in the following locales.

#### Alberta

(County of Mountain View, Edmonton, Lloydminster, Medicine Hat, Cold Lake, Red Deer, Rocky Mountain House, Lethbridge, Grand Prairie)

#### British Columbia

(Prince George, Victoria, West Kootenays)

#### Manitoba

(Brandon, Dauphin, Winnipeg, Belmont, Thompson, Morden/Winkler, Erickson, Neepawa, Portage La Prairie, Selkirk)

#### New Brunswick

(Moncton, Fredericton, Miramichi, Woodstock, Saint John, Bathurst)

#### Newfoundland

(Corner Brook, St. John's, Stephenville, Wabash, Clarenville)

#### Nova Scotia

(Halifax, Sydney, Truro, Inverness, Digby)

#### Ontario

(Almonte, Brantford, Cobourg, Durham, Peel, Niagara Falls, Peterborough, Toronto, Alliston, Simcoe/Port Dover, Sault Ste. Marie, Barrie, Belleville, Cornwall, Hamilton, Kingston, London, Ottawa, Smith Falls, Sudbury, Thunder Bay, Kitchener-Waterloo, Owen Sound)

#### Prince Edward Island

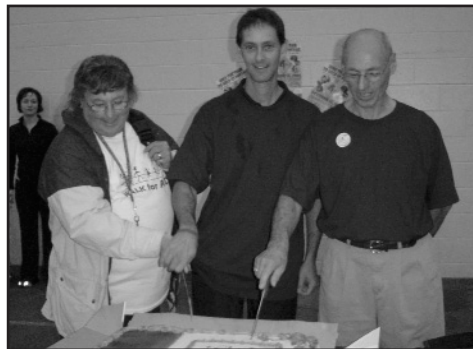
(Oyster Bed Bridge)

#### Saskatchewan

(Regina, Wynyard)



*Smiling for the camera are Nova Scotia staff members left to right Kerra AuCoin, walk co-ordinator and walk assistant Kyla Frank.*



*Cutting the cake from left to right is Briann Smith, ALS NS unit director and ALS Canada board member with Andrew Potbier, Halifax WALK for ALS corporate chair, and Art Macdonald, Halifax WALK for ALS family chair.*



*Colin Boyd pipes in the Nova Scotia walkers.*



## Hike the Trail to Help Us Prevail

Canadians across the country laced up their hiking boots on Saturday, October 15th joining ALS Societies across Canada as they hiked trails in support of research and client services for those living with this devastating disease.

**Hike 4 ALS** is a new program inspired by those living with ALS around the globe. It is executed nationally through ALS Canada. **Hike 4 ALS** targets outdoor enthusiasts of all fitness levels to participate in hikes that take place in local communities across the country. The hikes are designed to offer something for hikers of all skill levels and people from all backgrounds were encouraged to participate.

"One of the reasons we are so excited to launch the program is because we want to find new people to join the ALS team. The ALS community is relatively small and we created a new event that hopefully people can relate to. It gives

us the opportunity to introduce new donors and volunteers to the ALS Society and engage them in future programs and events," explains Joe Mangoff, development officer at ALS Canada.

The ALS Society of Canada and

Hi-Tec Sports sponsored the hike. This is the first year that the hike took place. Plans are underway for next year's hikes.

More than \$45,000 was raised for ALS research and support services in this inaugural year.



*The Kortright Centre (Vaughn, Ontario) hikers included:*

*Left to Right: Enzo and Julio Raponi, David and Pat Cameron, Anthony Debattista, Vito Umbrello, Robert and Enrica De Lorenzo, Ricky Iafrate, Dianna Mazzitelli, Mark Raponi, Bobbi Greenberg and Jane McCarthy*  
*Bottom Row: Daniel Debattista and Teresa Umbrello*

## ALS Canada Charity Golf Classic

On Tuesday June 7, 2005, 62 golfers teed off in support of ALS research and client services for those living with this devastating disease at the ALS Society of Canada Charity Golf Classic (in memory of Tim E. Noël). The Sleepy Hollow Golf and Country Club in Stouffville, Ontario was the perfect backdrop for this event.

Highlights of this year's tournament included poker sets for all participants courtesy of Freedom International Brokerage and the live auction of a Golf B.C. package including accommodation at the Crystal Lodge and rounds of golf at Nicklaus North, site of the 2005 Telus Skins game.

Participants also had the opportunity to test their luck at the hole in one contest with a three-year lease of a brand new Saab 93 on the line. Unfortunately, there were no holes in one recorded at the event. There were however, plenty of good shots, great food, and fun as more than \$64,000 was raised.

This event was made possible by the support of many sponsors and donors. For more information on the plans for the 2006 Charity Golf Classic please visit [www.als.ca/charitygolf](http://www.als.ca/charitygolf)

## Did You Know?

You can designate your United Way contribution to the ALS Society of Canada.

Ask your company United Way representative how.

## The Score Raises Funds for ALS

Monday, May 2nd, marked the 66th anniversary of the end of Lou Gehrig's consecutive games streak. *To the Point* with host Greg Sansone on The Score television network, devoted one hour to the subject of Lou Gehrig, focusing primarily on the disease that would later bear his name. The show took a detailed look at his brilliant career, a closer look at ALS, and contains a moving feature where Martine Gaillard interviewed two people who are living with ALS as well as the doctor (Dr. John Turnbull from McMaster University Medical Centre) who treats them. The show aired on May 2nd and again in July. After interviewing Elizabeth Grandbois and William Weir (who are living with ALS) The Score's Martine Gaillard decided she was going to

do something to help the fight against ALS.

"When I started working on the feature for our Lou Gehrig special I virtually knew nothing about ALS; meeting Elizabeth and William moved me like no other story I'd ever covered before...and I knew I wanted to do more," says Gaillard.

So Gaillard began collecting pledges around the office at The Score as a part of William Weir's Torch Team for Toronto's June 5th **WALK for ALS**. While this initiative was wonderful all in itself, the kicker was still to come. Upon hearing about her involvement in the Walk, The Score's owner John Levy challenged everyone at the network to donate, saying he would match every Score employee dollar with

five dollars. This amazing promise helped raised a remarkable \$4,680 towards research and support services.

With continuing support from people such as Martine Gaillard and John Levy the ALS Society will be able to continue to raise funds for research and support services as well as create awareness about this devastating disease.

The Score television network is a national specialty television service, which provides sports news, information, highlights, and live-event programming, available across Canada in more than 5.5 million homes. For more information check out The Score's web site at [www.thescore.ca](http://www.thescore.ca)

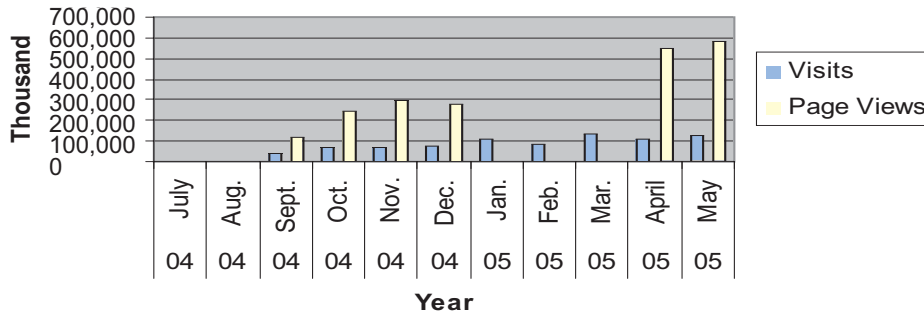
## Web Site Growth

Our web site - [www.als.ca](http://www.als.ca) - is visited by thousands of people each month and is recognized internationally as a timely and accurate source of news and information for people living with

ALS. It provides user-friendly information that is regularly updated with current content as well as offering a convenient means of donating online. We have seen more than a 300 per cent growth in visits from

June 2004 to June 2005 and more than a 500 per cent growth over the past three years. In September 2004 we had 40,000 visitors and in August 2005 133,655 people visited our site. The web site has grown both in popularity and in size; much of the visitor growth is due to our focused efforts to ensure new and updated materials are being added to the site regularly. The ALS Society of Canada appears among the first three sites on Google when you type in the letters ALS. Approximately 35 per cent of visitors find the ALS Society of Canada through a search engine while the remaining 46 per cent visit the site directly. As our web site continues to grow, awareness of ALS grows and we get one step closer to finding a cure for this disease.

**Web Site Stats 2004-2005**



## Call for Nominations

### Thérèse Casgrain Volunteer Award

Do you know an individual who has made a lifetime commitment to volunteering? Has their leadership and hard work somehow inspired partnerships with the public, private and voluntary sectors? If so then they may qualify for the annual Thérèse Casgrain Volunteer Award, an award that is given to one male and one female who have demonstrated a lifetime of dedication and commitment to volunteering.

Together with a bronze medallion, a lapel pin, and a certificate of recognition, award recipients will receive a \$5,000 donation that is to be given to a registered Canadian voluntary organization of their choice.

Candidates for the award may be nominated by an organization or up to three individuals. Nominations must include a detailed description of the candidate's achievements as a volunteer and must be submitted no later than the deadline date of Wednesday, February 1, 2006.

Nominations are open to all Canadians with the exception of elected government officials while serving in office, past recipients of the award and employees of Social Development Canada.

### About the Awards

The Thérèse Casgrain Volunteer Awards were created in November 1982 by Monique Begin, former Minister of Health and Welfare, to pay tribute to social pioneer and peace advocate Thérèse Casgrain. The award was reinstated during the International Year of the Volunteer in 2001 and is currently administered by Social Development Canada.

Complete guidelines are available on the Social Development Canada web site at [www.sdc.gc.ca/en/hip/sd/ThereseCasgrain/00\\_home.shtml](http://www.sdc.gc.ca/en/hip/sd/ThereseCasgrain/00_home.shtml)

### 10th Anniversary FLARE Volunteer Awards

Closing date for nominations is Friday, February 3, 2006.

She may be a friend, a neighbor, a coworker or even an acquaintance, she is someone who is giving something back to the community because she really cares. Her volunteer efforts are making a difference to the lives of the people around her. She deserves recognition and may be a candidate for the 10th Anniversary FLARE Volunteer Awards.

Six Canadian women will once again be honored at a gala event in Toronto in May 2006, as part of the annual FLARE Volunteer Awards. The awards aim to bring much-deserved recognition to those Canadian women whose volunteer efforts have made a difference in the lives of people in their communities.

### Award Guidelines

Nominees must be female, aged 18 or older by 2005, and a resident of Canada. A nominee's volunteer activities must be in association with a Canadian organization; however, the actual work may have taken place at the national or international level.

Nominations are being considered in three award categories including youth, community and leadership, and lifetime achievement.

To view previous recipients of the Flare Volunteer Award or obtain a copy of the 2006 official nomination form, visit <http://www.flare.com/volunteer/index.jsp>

## The New ALS Society SEED Grant Program

**E**arlier this year, the ALS Society of Canada initiated a new program called the **S**ervice and **E**ducation **E**nhancement and **D**evelopment (SEED) Grant Program to assist provincial ALS societies with outreach and service delivery.

David S. Cameron, national executive director says, "This new initiative was developed as a pilot program and will be funded at \$65,000 for 2005. The program was designed to provide financial support for provincial ALS Societies wishing to further develop their service delivery capacity, thereby increasing the quality of life for those people living with ALS."

Seven grant applications were submitted for funding and five of those have been approved for funding. The applications were evaluated by a review committee using a scoring system to measure the quality of information and the relevance to the SEED Grant Program. Those applications were then sent to the ALS Canada executive committee for approval. ALS Canada is pleased to announce the 2005 Grant Program award recipients.

### **ALS Personal Care Aide Training Program** - ALS Society of Alberta

This program aims to improve the quality of ALS home care in the province of Alberta through developing and implementing training programs designed for paid caregivers to provide care for those living with ALS. In the beginning stages training materials and curriculum will be developed (caregiver training manuals previously created by the Alberta Society will be expanded and modified and existing film footage will be used to produce a video), team leaders and key trainers from both Southern and Northern Alberta will be identified and trained. The training courses will be piloted once in both the north and south for 40 trainees.

### **Community Support Initiative - Peer Support Program (for ALS Caregivers)** - ALS Society of Ontario

In response to an identified need to provide better community support to family care-

givers, this initiative aims to develop peer-support models for caregivers to be provided by community volunteers with staff support. Three types of support models (mentor program, pairing program, and caregiver only support group) will be implemented in various stages. Initially, the Society will partner with the staff at the McMaster Health Sciences Centre ALS Clinic to help identify and train former caregivers as "mentors" for current ALS family caregivers. The Society is working with the Wellspring organization to adapt its model of peer support for cancer caregivers to the ALS community. This is a pilot program the Society hopes to expand throughout the province of Ontario in the future.

### **En Route with the ALS Society** - ALS Society of Quebec

Because 60 per cent of registered clients live outside of Montreal, where services have been traditionally focused, the ALS Society of Quebec decided to expand into additional regions to increase awareness, better understand and respond to members' requests, and provide services across the province. The project consists of a road show of a team of ALS Society of Quebec representatives into four regions of the province. The day long "show" will include a press launch, a lunch targeting local health-care providers, a caregiver get-together, volunteer information session, one-on-one time with the social worker, and an evening support group meeting. With this project, the Society hopes to also develop interest and resources for additional ALS Walks to continue to sustain regional programming.

### **1st Annual ALS Education and Awareness Program/Outreach Co-ordinator** - ALS Society of New Brunswick

This project aims to increase ALS New Brunswick's capacity to provide information and awareness about ALS, the Society, and the Stan Cassidy Rehabilitation Centre ALS Clinic services. Through hiring an outreach co-ordinator, they can execute their plan to bring an ALS Education and Awareness Program to six of the province's major cities

over the course of five months. A team of Society directors and members of the ALS Clinic team will hold two meetings in each city: one for members of the health-care community and one for families living with ALS and other interested parties. This project will enable the Society to better identify clients as well as potential volunteers and donors throughout the province. With this information and new relationships, the Society hopes to develop districts in each area to better serve people with ALS on a local basis

### **Volunteer Family Advocate Friend (VFAF) Pilot Program** - ALS Society of Manitoba

The VFAF Program aims to be a model for an in-home volunteer visitor program providing specialized support for people living with ALS and their family members. Funding for this program will assist in hiring a project co-ordinator to manage the day to day operations of recruiting, screening, and training volunteers. A partnership with Hospice and Palliative Care Manitoba has enabled this organization to play a role on the project advisory committee and assume a leadership role in volunteer screening, client assessment, and case management. Once a co-ordinator is hired, this organization will act as his/her mentor in these areas. During the pilot phase, the program will serve up to six families with two volunteers each for a total of up to 12 volunteers recruited, screened, trained, and placed. The pilot will be evaluated with results shaping plans for expansion (more families) and specialization in terms of types of support (e.g., children's support issues, bereavement).

This being the pilot year, the SEED Grant Program will be evaluated in terms of progress and grant outcomes and improved for upcoming years. "The purpose of the SEED program is to ensure all ALS provincial Societies have the means to provide the best possible support services to those people affected by ALS. This fulfills our goal of making every day the best possible for those people living with ALS," says Cameron.

## ALS Ontario's DAY IN THE PARK

In November, ALS Ontario held its second DAY IN THE PARK - advocacy and awareness day at Queen's Park in Toronto, Ontario. The advocacy committee set up 14 appointments with MPPs, mainly those with an interest in health and disabilities issues, from all three parties. They also met with staff from the Ministry of Health and Long Term Care and with staff from the official opposition.

The visitors were volunteers and staff from the Greater Toronto area including William Weir, Lynn Hood, Tim Robertson and Bruce Wilson, all of whom are living with ALS.

Teresa Rivero, chair of the advocacy committee reports that: "Our advocacy day at Queen's Park was very successful. Our objec-

tive was to inform, support, and provide an avenue for the government to test and implement the changes to the Community Care Access Centres System as recommended in the Elinor Caplan Report.

"We offered the ALS Society of Ontario as a viable, manageable, and measurable group ready, willing, and able to provide a testing ground for these recommendations through our Service Delivery Model.

"Our offer was keenly received. The ALS Society of Ontario has been invited to participate in the implementation process with the Ministry of Health and Long Term Care. We view this as a major step towards ensuring that the Home Care needs of those with ALS in Ontario are effectively met."

### Service delivery model

In April 2001, the ALS Society of Toronto (merged with ALS Ontario in 2004) completed the development of an ALS service delivery model that incorporates:

- client-centred approach
- continuum of care, including palliative care
- service delivery process
- decision-making process to care
- strong foundation of governance and accountability through client, family, and health care service standards and outcome measures
- community linkages and partnerships
- levels and types of services that meet specific client needs
- adaptability, flexibility, innovation and creativity

## Grade 6 Student Donates Funds from Class Project to ALS Canada

Alex Dawson, a grade six student at Rolph Road Public School, located in Toronto, Ontario, completed a school project - Student Philanthropy Initiative - about ALS and helped to raise funds and awareness for this disease. The Philanthropy Initiative has become an annual project for the grade six students attending Rolph Road. Brian Deeks, a grade six teacher created this unique project where students are asked to choose a charity of their choice, research it, do a personal interview, create a poster and give a presentation to their classmates. The project provides an opportunity for the students to demonstrate reading, writing, oral communication and, visual art skills.

Dawson chose the ALS Society because his grandmother passed away from ALS two years ago and he wanted to learn more about it.

"When I read about all the people that live with ALS and have died from it, I thought that even though I don't have ALS now sometime later in my life I may have it. I came to appreciate life more after this project knowing how fragile it really is," explains Dawson. An additional component to the project includes raising funds for the students' charities. Alex and his fellow classmates participated in selling freezies, baked goods, and bracelets. The class raised \$1,500, the Home and School Association gave them an additional \$1,000, and the Geoffrey H. Wood Foundation donated \$1,000 as well. The grand total of \$3,500

was divided among the students to give to a charity of their choice. Alex donated his portion, \$113, to the ALS Society of Canada.



*Left to right – Alex Dawson and Bobbi Greenberg, director of communications, the ALS Society of Canada at Rolph Road Public School.*

## 2nd Annual ALS Client Services Day

The ALS Society of Canada held its 2nd Annual ALS client services day on June 15, 2005 in Ottawa.

"The client services day is designed to facilitate professional and peer networking, and, sharing best practices. This year included a two-hour workshop on coping with cumulative loss when you are in the role of an ALS clinical care or community-based service provider," said Jane McCarthy, MSc, MPH, director of services and education for the ALS Society of Canada.

In attendance were ALS Society client services staff and ALS clinical-care providers from across Canada. Guest speakers included: Susan Carroll-Thomas, RD, Ottawa Rehabilitation Centre; Gwyn Moe, physiotherapist, GF Strong ALS Centre in Vancouver; Diana Rasmussen, RN and executive director ALS Society of Manitoba; Christina Clark, RN, ALS Society of Manitoba and the Brummitt-Feasby ALS House; Jane McCarthy; Marion Williams, regional manager, ALS Society of Ontario,

Champlain Regional Office; and, Vivan Stang, chaplain, Ottawa Rehabilitation Centre.

Topics covered included: an update on activities of the ALS Society of Canada's service delivery task force, presentations on exemplar clinic services and society programs and projects, discussions regarding collaborative models of service delivery and the exploration and management of cumulative loss and grief among service professionals.

## Promoting Excellence in End-of-Life Care in ALS

"Promoting excellence in end-of-life care in ALS" is a comprehensive article that was recently published in the September 2005 issue of *Amyotrophic Lateral Sclerosis and other motor neuron disorders*. And, one of the authors was ALS Canada's director of services and education Jane McCarthy.

### Abstract:

The type and quality of end-of-life care varies greatly in ALS; the time to initiate end-of-life care is not defined, and decision making is hampered by logistical and financial barriers. There has been no systematic review of these issues in ALS. The goals of

this initiative are to:

- 1) improve end-of-life care for patients with ALS and families based on what limited evidence is available;
- 2) increase awareness, interest, and debate on the end-of-life care in ALS; and
- 3) identify areas needed for new prospective clinical research.

The ALS Peer Workgroup reviewed the literature and

- 1) identified the current state of knowledge,
- 2) analysed the gaps in care, and
- 3) provided recommendations for standard of care and future research.

It was shown that areas of inves-

tigation are needed on the incorporation of an interdisciplinary approach to care in ALS that includes: psychosocial evaluation and spiritual care; the use of validated instruments to assess patient and caregiver quality of life; and the establishment of proactive caregiver programs. Several public policy changes that will improve coverage for medical care, hospice, and caregiver costs are also reviewed. More clinical evidence is needed on how to provide optimal end-of-life care specifically in ALS.

Authors: Hiroshi Mitsumoto, Mark Bromberg, Wendy Johnston, Rup Tandan, Ira

Byock, Mary Lyon, Robert G. Miller, Stanley H. Appel, Josh Benditt, James L. Bernat, Gian Domenico Borasio, Alan C. Carver, Lora Clawson, Maura L. Del Bene, Edward J. Kasarskis, Susan B. Legrand, Raul Mandler, Jane McCarthy, Theodore Munsat, Daniel Newman, Robert L. Sufit & Andrea Versenyi.

*Amyotrophic Lateral Sclerosis and other motor neuron disorders*, Volume 6, Issue 3, September 2005, official publication of the World Federation of Neurology Research Group on Motor Neuron Diseases. For reprint information contact johanna.rydhem@tandf.no

## Researchers Uncover New Toxic Mechanism in ALS

Exactly how ALS — Lou Gehrig's disease — damages motor neurons is one of medical science's lingering mysteries. At least six mishaps within cells appear to contribute to the death of the nerves that enable muscle movement, but nothing stands out as the key problem. Packard investigator Jean-Pierre Julien.

Now new studies by a Canadian research team and Japanese collaborators, with support from the Packard Center for ALS Research at Johns Hopkins, strengthen earlier theories that whatever ultimately tips motor neurons onto their downhill path likely comes from outside the cells. The work describes a mechanism in which a warped, toxic molecule is secreted from cells into a motor neuron's environment, where it harms the neuron.

The studies, which are described in this month's issue of *Nature Neuroscience*, could focus therapy research on easier-to-access areas outside of cells.

Led by Packard scientist Jean-Pierre Julien of Quebec's Laval University, the work is largely based on mouse models of ALS

— animals engineered with a mutant human gene responsible for a familial form the disease. Mice carrying the mutant SOD1 gene develop ALS and die. Those with normal SOD1 are fine.

In earlier novel studies where only some mouse cells carried mutant SOD1 genes, Julien's team showed, to their great surprise, that even though motor neurons may carry mutant genes, they apparently don't die as long as neighboring cells' SOD1 is normal. And, conversely, having neighbors with mutant SOD1 can trip motor neuron death even if the motor neurons themselves have the healthy version. Other Packard scientists has confirmed the unusual results that point to the importance of a motor neuron's surroundings in developing disease—what they call the "bad neighborhood" theory.

In the new studies, Julien's team found that misshapen, mutant SOD1 is preferentially "booted out" of nervous system cells — secreted by motor neurons and other neighboring cells — into cell surroundings. Once there, the researchers show, the mutant

SOD1 is directly toxic to motor neurons it encounters. It can also rouse nearby immune cells, the microglia, which themselves release neuron-harming agents.

The team's studies began with a fishing expedition of sorts, using a yeast two-hybrid approach, a modern technique that uses a cell protein as "bait" to see what other molecules associate with it. Mutant SOD1 was consistently linked with chromogranins — molecules closely tied to cell-secretion systems. In both nerve-cell cultures and in the spinal cords of the model mice, the team observed mutant SOD1 — but not normal SOD1 — paired with chromogranins. Further, the scientists found the pairings throughout a cell's secretory machinery, a "packaging" system called the trans-Golgi network. The older the mice, the more paired molecules appeared. "We believe that chromogranins chaperone the mutant SOD1, helping it through a cell's secretory pathways," says Julien.

Last, the researchers discovered that chromogranin production, and, accordingly, mutant SOD1

secretion, is dramatically stepped up in cells adjacent to motor neurons, bathing them in the misshapen molecule. "In a motor neuron that's under siege from events within," Julien says, "having toxic molecules outside may be a last straw in the cell's coping ability. All this," he says, "becomes a part of ALS pathology that hasn't been explored."

The research was supported by the Robert Packard Center for ALS Research at Johns Hopkins, The ALS Association, the Canadian Institutes of Health Research, the ALS Society of Canada, the Japan Society for the Promotion of Science and Japan Foundation for Neuroscience and Mental Health.

Scientists participating in the study are Makoto Urushitani (the first author) of Laval University and Attila Sik, Takashi Sakurai, Nobuyuki Nukina and Ryosuke Takahashi of the RIKEN Brain Science Institute in Saitama, Japan.

*Dr. Julien is an ALS Canada board member.*

*Source: Johns Hopkins Medical Institutions  
Released: Friday, Jan. 6, 2006  
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## Change Your Attitude, Change Your Life

By Mike Speelman

*The greatest discovery of my generation is that a human being can alter his life by altering his attitudes. – William James*

**W**e have ALS. Now what? We can choose to be morose and dour for the remainder of our time, or we may accept the disease as a part of our particular make-up and strive forward. This article will choose the latter to focus on. Although the more difficult road, it is also the more salutary. On we go...

Since being diagnosed in 1993, I have spent quite a bit of time reading books on the disease, trying to get a handle on this thing that has invaded my body. I read over and over about the physiological aspects of the neurons and the impulses carrying messages to and from the brain. As well, I read time and again how there is no definite cause and certainly no cure. I felt as though I had to be missing something...but what?

A friend once told me "You have to become an expert in your own disease." I thought I had. I thought I would attack this from a different angle. I decided to study how to deal with disease, not the disease itself. ALS is a constant, something that will not change. The variable in this equation is us.

"It's life Jim... but not as we know it."

– Star Trek's Mr. Spock

Life has changed for us. Not the change we pictured in our youth as we grow old with our loved ones, but a change nonetheless. When one is touched by physical or emotional strife, it is inevitable and perfectly natural, that we go through the five stages of grief:

1. Denial: "No, you couldn't mean me." Sound familiar? I always advise people to get second, even third medical opinions. Myself, I had seven different opinions. Talk about denial.

2. Anger: "Why me?" The mantra of all who have been stricken by disease, misfortune or the general discord life brings. Another slant to the same question...

"Why not you?"

3. Bargaining: "Lord, cure me of this affliction and I promise I will INSERT ANSWER HERE" This was my prayer. No

matter what deals you conjure up or who you promise them to, the situation will remain the same. Remember, ALS is the constant.

4. Depression: "Hello darkness my old friend" (The Sound of Silence, Simon and Garfunkel). This is a very important stage. It is so important to not get mired in any one of these stages, especially depression. It can be a dark pit from which escape seems impossible, but we must! Climb, scrape, use our hands and grip with our fingernails but we must get out of the pit! Our very survival depends on it. Once we reach over the edge we can move to...

5. Acceptance: here we are! The meeting place of those who have traveled the road before you.

Now that we have come through this obstacle course of the five stages, we can focus on the life ahead. We must address the fact that we are not the only ones suffering with this disease. Our wives, husbands, children, friends, and relatives all share our pain. Believe me – they feel it when we fall. Their hearts ache when we get to the point of needing equipment or invasive procedures. We think we are alone, but we are never, ever alone. When we suffer, they suffer.

On the other end of the spectrum, when we feel good, they feel good! I don't want to sound like a Pollyanna about having ALS, but it has been proven that attitude, whether it is good or bad, is infectious! Think about a time in your life when you have been around someone who is negative. Someone who finds fault in everything and everyone. Remember how you counted the seconds to get away from them? Remember how you felt afterwards? Drained, depressed and probably tired. Now think of a time when you were with someone cheerful, positive and full of life! You come away from that encounter with spring in your step, hopeful, probably even whistling. We are the catalysts that can send our family and friends away from us either whistling or tired. Which would you rather?

We are dying! No surprise there, we have

ALS. Guess what? We were dying before we had ALS. Mind you, at a greatly reduced rate, but dying nonetheless. The difference? Now our focus is on that aspect, where before, we took mortality for granted. You must ask yourself, "Do I spend what little time I have left focused on dying and the disease or do I focus on *making every day the best possible*, states the motto for the ALS Society of Alberta."

To change our attitude we must address

1. Acceptance
2. How we identify ourselves
3. Focus

Acceptance - The first thing we have to accept is that ALS is now part of our lives. Once we stop the fight - the war against the disease, we can relax. If the conflict rages within us, it will only result in increased stress and anxiety. Stress will compromise our immune system and lead to further disease in the form of high blood pressure, heart disease, flus, colds or a host of other illnesses. This is not my opinion, this is medical fact. I'm not saying give up, on the contrary, I'm saying end the battle. No winners. No losers. Just peace. Wouldn't that be nice? You must admit to yourself that ALS is part of your body now. You can cry and yell all you want, but it isn't going away. Look in the mirror. Tell yourself, "I'm still me! I just happen to have ALS. Beyond that, I'm still me!" It takes time but slowly you will find that you are more relaxed about...everything. If you are at ease and centered, those around you will be the same because your attitude is infectious! You may want to look into practicing meditation and proper breathing. It truly does your body and mind wonders.

How we identify ourselves - Don't get in the habit of identifying yourself as having ALS. As I said above, you are defined by you. You are not defined by the disease and don't ever let anyone try. It would be like defining yourself by your elbow. "Hello, I'm Mike and I have an elbow." That doesn't make sense. People will inevitably give the

Continued on Pg. 15

**Continued from Pg. 14**

"Awww, you poor dear" greeting. Just sit up, smile and show them they have nothing to feel bad about because you certainly don't. There are going to be times when you don't feel up or positive. It's perfectly natural. Everyone goes through it. The danger lies in becoming too comfortable in that mood. Again, think about your focus.

Focus - Switch your focus off you and ALS to something positive in your life. Impossible, right? Perhaps. But you have already demonstrated great courage in the face of insurmountable odds by coming through the five stages of grief unscathed.

"What does not destroy us - we destroy, and it makes us stronger." – Friedrich Nietzsche

For a long time, I felt sorry for myself. I was stuck in the depression stage. But, with the help of family and friends kicking my ... along the way, I was able to clamber out of the darkness. Once in the light, through squinting eyes, I saw my beautiful wife, my handsome son and my little baby girl. I swore from this point on, they would be my focus. I had been focusing on me, the disease, dying and everything I can no longer do. What I had to do was change my focal point. Before ALS I could do maybe 10,000 things (give or take 100)! Now I can do

maybe 4,000 things. So, do I focus on the 6,000 things I can no longer do, or the 4,000 things I still can?

There are so many beautiful things in the world. Make a pact with yourself to spend what little time we have left looking outward instead of inward. Always remember that life does not end at the diagnosis.

"And in the end, it's not the years in your life that count. It's the life in your years."  
– Abraham Lincoln

*Mike Speelman is a past president of the Edmonton Chapter of the ALS Society of Alberta. He has had ALS for approximately 11 years.*

## Board Members in the News

### Maritimer of the Week Goes to Briann Smith

ALS Canada board member Briann Smith was recently nominated for CTV's Maritimer of the Week. Through nominations CTV selects various Maritimers who make outstanding contributions to their community.

After losing a close to friend to ALS 14 years ago, Smith and a small group of committed volunteers recognized the need for an ALS unit office in Nova Scotia. Like the phoenix which rose from the ashes, Briann and his team resurrected what there was of a society in Nova Scotia.

Jennifer Gardiner, client services co-ordinator at the ALS Society of Nova Scotia explains, "We started with three canes and a bath-bench. Today, those living with ALS and their families and caregivers are supported with equipment and services that allow clients to remain in their homes instead of being hospitalized."

Smith has a busy law practice; however, he still takes the time to be extremely involved with the ALS Society of Nova Scotia. For the past 14 years Smith has been the president of ALS Nova Scotia, is a past president of the ALS Society of Canada, and is an ALS Canada board member.

On October 14, Smith received a certificate of recognition for his efforts from ALS Nova Scotia staff, board members and patient representatives.

"I was extremely honored by this award and

needless to say, very surprised when I walked into my office from court to find a television crew, fellow board members, ALS NS staff and my law office staff waiting for me. During the presentation I was further rewarded by meeting yet another client of our Society, Jean Behan and her principle caregiver and husband Reg and was again confident that the success of what we do for our clients is well worth the time and effort involved. We can make a difference! More importantly than personal reward is that this show is seen throughout Maritime Canada and was a wonderful awareness vehicle for the ALS Society," says Smith.

### Gloria Miller Saves Baby from Burning House

Congratulations go to Gloria Miller, president & unit director of ALS Saskatchewan for her amazing bravery. In the summer of 2004, she was sitting in her backyard when she noticed smoke billowing from a house across the lane. She ran to the smoke-infested house and managed to get the mother and her nine-month-old baby safely out of the house. Without her bravery, the baby wouldn't have survived.

The Saskatchewan Centennial Medal celebrates people who give generously of their time and energy to improve the lives of others. Recipients are selected based on the recommendation of governmental and non-governmental organizations and Members of the Legislative Assembly. Community leaders, MLAs, MPs and judges also receive this prestigious medal.



*The Saskatchewan Centennial Medal was presented to Gloria Miller for her work with ALS, as well as for getting the people out of a burning house. Linda Haverstock presents Gloria Miller with the Centennial Medal.*

## 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.

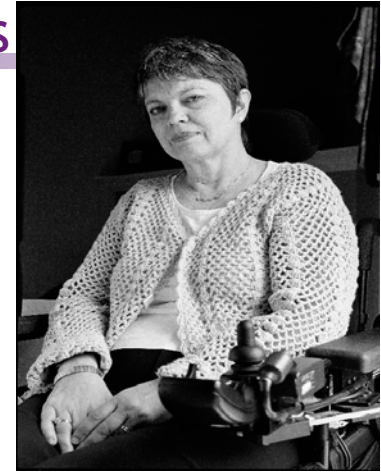
Please consider providing a planned gift to the ALS Society of Canada.

**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 doc-

- umentation, i.e., a 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 416-497-2267 ext. 228 for assistance.



Elizabeth Grandbois

## ALS Society Welcomes New Staff Members

Joining the ALS Society of Canada team on a permanent basis is Joe Mangoff as development officer. Mangoff was hired six months ago as the **Hike 4 ALS** co-ordinator and will now be responsible for both the **Hike 4 ALS** and **WALK for ALS**, along with other key event and sponsorship responsibilities. He replaces Matthew Wiesenfeld who has moved on to Basketball Ontario as the manager of communications and marketing.

ALS Ontario welcomes back Nelly Teitelbaum as manager of finance.

The ALS Society of Quebec has a new staff person joining its team - Desaria Bradshaw as co-ordinator, client services.

The ALS Society of New Brunswick has hired its first staff person - Bernice Léger as the administrative assistant on a part-time basis.

The ALS Society of Nova Scotia has two new staff members - Laurie Appleby, fundraising and marketing director and Kyla Frank, assistant walk co-ordinator.

The ALS Society of Manitoba has hired two

new staff members, Darlene Van Ruiten as director of development and Sharon Carter as administrative assistant.

The ALS Society of Alberta has hired Lauren Milburn as the co-ordinator of the Society's equipment program.

And, on the west coast at ALS BC there are three new staff members: Kelli Seepaul, communications director, Lisa Hercus as patient services co-ordinator and Rena Mendoza as donor relations & office administration. Welcome Aboard!

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