

# Coast to Coast

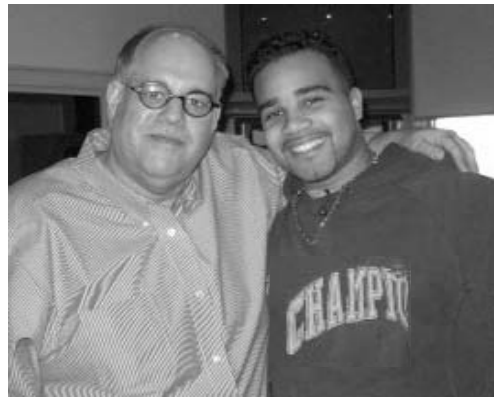


Spring 2008

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## TORONTO STUDIO HELPS CREATE PUBLIC AWARENESS MAGIC



The radio PSAs were recorded at RMW music by Ted Rosnick, CEO & producer and Tyson Kuteyi, studio technician.

**W**ALK for ALS is about to hit the big time. On February 28, ALS Society of Canada's director of communications, Bobbi Greenberg, headed into the recording studio to produce radio public service announcements (PSAs) for the upcoming Walk season.

Two PSAs were created: a 30- and 60-second slot. Radio stations will choose which version they use, depending on the amount of programming time available. The PSAs were produced pro bono by RMW Music, an award-winning post-production house located in downtown Toronto.

"We're delighted to be involved with this project," says Ted Rosnick, founder,

CEO and producer, RMW Music. "We think this is a great cause and hope the PSAs generate a lot of buzz."

The PSAs feature music familiar to the ALS community: the music was originally written for the award-winning television PSA "Hugging," created by ALS Canada's former advertising agency BBDO Toronto for the "What Would You Do, While You Still Could?" campaign.

The music was written by Toronto-based musician Jim Guthrie. Voice talent was provided by Elizabeth Ramos, a veteran voice actress who has lent her voice to a variety of projects, including cartoons and commercials, in Canada and the United States.

"I was glad to work with ALS Canada," says Ramos. "Just before our session, I had lunch with a friend who lost someone to ALS. I dedicated this project to that person."

Tune into your favorite radio station between April and September to hear the PSAs which promote the WALK for ALS.

Visit [www.walkforals.ca](http://www.walkforals.ca) for more information about the Walk.

## 2008 WALK SEASON LAUNCH

**W**e're heading to the streets, paths and trails to help people living with ALS. The WALK for ALS, a partnership between the ALS Society of Canada and the nine provin-

cial societies, is an annual fundraiser held in more than 70 communities nationwide between May and September. In 2007, the Walks raised more than \$2 million.

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



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

**F**all 2007 was a busy period marked by growth and the exchange of ideas with members of the ALS community from near and far.

On December 1-3, ALS Canada hosted the 18th International Symposium on ALS/MND. Scientists, clinicians and people with ALS from around the world converged on Toronto. This is the second time the Symposium has been held in Canada and the first time it has been held in Toronto.

Researchers presented papers and posters on their work in the areas of basic and clinical science.

Topics discussed included genetics, animal models of ALS, immunization, and clinical care techniques and

innovations. The Symposium followed the 15th Annual Meeting of the International Alliance of ALS/MND Associations, held November 28-30.

In November, we hired a new vice-president of development, Scott Fortnum. Scott has extensive experience in fund development, having served as the national development director at Ducks Unlimited Canada and regional vice-president at DVA Navion before joining ALS Canada. Scott has a master's in philanthropy and development and holds a Certified Fundraising Executive (CFRE) designation. Under Scott's leadership, we expect to increase

donations and enable our plans for increased research spending.

November also saw the publication of new manuals for children and teens. Developed by Jane McCarthy, director of services and education, the booklets offer valuable information about ALS and personal accounts from children of people with the disease: i) When Your Parent Has ALS: A Booklet for Teens, ii) When Someone Special Has ALS: A Booklet for Children, and iii) Helping Children Cope With ALS: A Parental Information Guide, are available for download at

[www.als.ca/als411](http://www.als.ca/als411).

Please contact your provincial society for a hard copy.

In January 2008, we launched the new WALK for ALS web site, [www.walkforals.ca](http://www.walkforals.ca).

The new site replaces the former domain, [als.ca/walkforals](http://als.ca/walkforals). The new site offers easy-to-use features that allow visitors to search web sites by a personal or team name to make pledges of support. The site connects participants from all three annual fundraising initiatives: the WALK for ALS, the Hike 4 ALS and Betty's Run for ALS. There is also a sec-

tion for third-party event fundraisers. Participants must register in one of the events to join the online community and set up their own site, where they can collect online donations. Users may also download forms and canvass the old-fashioned way. Check the web site regularly, as Walk locations will be added as they are set.

In addition to launching the Walk web site, staff members travelled to Halifax in January and Edmonton in February to conduct WALK for ALS training sessions. Similar training was provided to the volunteers in Ontario last November. Provincial staff and volunteers were trained in team-building, budgeting, media relations and web site creation. Training manuals have also been created for Walk volunteers and will be distributed by the provinces.

Finally, the ALS Society is pleased to announce that we are committing more than \$1.5 million to research spending in 2008, the most we've spent in the organization's 31-year history. We thank all volunteers and staff for their hard work and look forward to the promising year ahead.

## ALS CANADA LAUNCHES NEW ADVERTISING PROGRAM

The ALS Society of Canada has launched a new advertising program that will expand beyond the organization's former media outlets, which have included newspapers, magazines, transit advertising and cinemas, to now include television and internet advertising.

Television dot spots publicizing the Walks will be airing on Global Television

on Wednesday evenings between 7 - 11 p.m. from May 28 to June 16. Dot spots are five-second-long promotional slots appearing during highly targeted television programs, directing viewers to the [www.walkforals.ca](http://www.walkforals.ca) web site.

Google search advertising of the Walks will also be available during the months of May and June, directing users to the Walk

site based on various keywords entered into the Google search engine.

Three one-page color supplements will also be published in *The Globe and Mail* on May 14, 21 and 28. Among the topics covered include: research breakthroughs; living with ALS; ALS clinics; and, advance care planning and end-of-life issues.

In addition, RMW Music, a

Toronto-based post-production house, has produced two new radio public service announcements promoting the Walks, pro bono. Please see the article on Toronto studio helps create public awareness magic on page 1.

And, in the fall, we will be running print ads in the French media including *Coup de Pouce* and *Sélection RD*.

## MP PAUL DEWAR SUPPORTS ALS AWARENESS IN THE HOUSE OF COMMONS

On October 26, 2007, MP Paul Dewar (Ottawa Centre), addressed the House of Commons with a speech on the ALS benefit work done by the Peloso family.

*"Mr. Speaker, this Saturday the Peloso family in my riding of Ottawa Centre will be organizing the sixth annual fundraiser and awareness night in support of the ALS Society of Ontario. ALS is a fatal disease commonly referred to as Lou Gehrig's disease.*

*Many Canadians and their families have suffered from the consequences of ALS but they stay strong because of the support of their families and their communities.*

*The Peloso family had only six weeks to say goodbye to their beloved father from the time when he was diagnosed to the time when he passed away. At the time there was little public awareness of ALS and virtually no community support.*

*However, the family turned the tragedy into positive energy. They came together to raise*

*awareness, build community, and to date have raised over \$73,000 in support of the ALS Society of Ontario.*

*On behalf of the residents of Ottawa Centre, I congratulate the Peloso family and the organizers of this event for their hard work."*

Since 2002, the Peloso family has organized an annual dinner gala and concert in hopes of raising much needed money to aid research initiatives in the fight against ALS.

The Pierino Peloso Fundraiser Dinner Gala and Concert took place on October 27<sup>th</sup> at the Cleo Banquet Hall in Ottawa. The event raised

\$22,000 for ALS with an attendance of approximately 375 guests, including MP Paul Dewar and Zack Werner, Canadian Idol judge and the WALK for ALS spokesperson.

Pierino Peloso, 68, was diagnosed with bulbar ALS in February 2000. Bulbar onset ALS typically affects the muscles in the throat, mouth, face and jaw first, making speaking, chewing, swallowing, eating and breathing a challenge. Because of this, people with bulbar ALS usually have a shorter survival time than people who develop other forms of the disease. Peloso passed away less than two months after diagnosis.



## LIVING WITH ALS

## Proudfoot savours every moment; Forman ALS battle a

**O**n May 7, 2007, my life changed forever. That was the day Dr. Angela Genge of the Montreal Neurological Institute informed my wife Vicki and me that I had Amyotrophic Lateral Sclerosis, or Lou Gehrig's disease. It is a motor neuron disease, progressive and ultimately fatal, whereby all the muscles in your body slowly waste away until you eventually die of respiratory failure. There is no known cause, no effective treatment, and currently very little hope for a cure in the near future.

I cannot convey the feelings of shock and helplessness Vicki and I had that day. As we sat there, staring at each other, the cold reality of this devastating diagnosis enveloped us, and we knew our future had just been permanently changed. We tried to portray a couple in control, but it was impossible; the astonishment and fear of this situation were flooding our thoughts. It would take us a while to realize this type of situation would require a whole new way of looking at things.

I had been reading up on the disease over the previous month, while undergoing tests to determine what was causing my slurred speech. I had started to notice a change in my voice while I was lecturing at Concordia University in late February. There is no definitive test for ALS, therefore you are subjected to a battery of procedures, trials and examinations, hoping to find a benign cause of this apparent neurological problem.

Many other potential neurological conditions were ruled out by the end

of April. As my symptoms and impairments progressively moved to muscle fasciculations (twitching), excessive yawning, uncontrolled emotional swings and more slurred speech, there was no other conclusion except ALS to explain my physical changes. The official diagnosis is Bulbar Onset ALS, meaning the first muscles to be affected are the ones where the motor neurons exiting the brain stem control speaking, swallowing and breathing.

It often seems tragedy happens in an almost calculating, targeted way. The fine watchmaker's eyes go on him. The gifted artist or musician gets severe arthritis. The loving old man begins the downward Alzheimer's spiral and starts losing the capacity to love and mentor a myriad of kids and grandchildren. That irony is also not lost on me.

I have spent my entire life as an athlete and played nine seasons as a defensive back with the Alouettes during the 1970s. I have always been active and promoted a healthy, dynamic lifestyle only to contract a muscle-wasting disease, a disease you cannot treat or alter. To emphasize the paradox, I now make my living as a broadcaster and teacher, and the first thing that is going is my ability to speak.

Absurd, cruel, nasty, even evil! So what now, you ask? My fate has been decided, but not the rest of the life I have to live. I choose to smile, laugh, connect with friends, and be as positive as I can be. The often-used, seldom-practised idiom "Live life to the fullest" has never meant more to me



**Tony Proudfoot**

than right now and for every single day I have left.

What I have found out is something I should have figured out a long time ago. Life is good with the right attitude. Life is really good.

This past season with the Alouettes, as part of the CJAD broadcast team with Rick Moffat and Ed Philion, was extraordinary, and not because the team played so well (duh!), but because I made a conscious effort to fully experience the moments, the day-to-day highlights of ordinary life.

I knew I wanted to remain connected to football and the CFL, so I met with Moffat privately in May and he supported my desire to continue being on the Alouettes radio broadcast team. Unfortunately, ALS deterioration is a constant, and by the first exhibition game my voice had deteriorated to the point that I occasionally sounded a bit like a drunk. Rob Braide, the station manager, began receiving complaints. I had anticipated this event, recognizing that my voice wasn't up to broadcast standards and therefore decided to go public with my affliction in an

## er Alouette lives life to the fullest as he wages courageous and comes to grips with his fate

attempt to clarify the situation, protect CJAD's reputation and sensitize the listeners and public in general.

I took advantage of an Alouettes pregame news conference to announce to the national football media that I had ALS, and that opened the floodgates. For the next six months, and counting, I have become a public face for this crippling disease.

I began to appreciate and relish this opportunity to be a spokesperson. I now realize that I can make a difference, advocating and organizing support for this devastating, but relatively obscure condition. Only two in 100,000 people are afflicted with this disease. And if you are not affected by ALS, it's unlikely you would be aware of it and, consequently, unlikely to donate to much-needed research funds. It becomes a vicious circle, however, when there's not enough awareness, there's not enough funding.

My broadcast and media contacts throughout Canada, along with my 12-year CFL playing career, is allowing me to generate considerable exposure through radio, newspapers and television. Since June, I have conducted 34 interviews, many of them broadcast nationally. I have been contacted by 28 ALS patients and raised almost \$40,000 for ALS research. I continue to heighten awareness and contribute to growing fundraising initiatives.

For example, Larry Smith, my former teammate and CEO of the Alouettes, has agreed to host/sponsor an ALS fundraising event next year [2008].

There are also other initiatives in the works.

I have always been one to recognize a problem and, true to my personality, decided to do something about it. I learned a lot playing football and in athletics in general. I could go on for hours about the parallels of playing a game well and being successful in life. For example when you fail at something - miss a tackle, flunk a test, lose a job or whatever - you have lots of choices. If you see it as an opportunity and focus on a solution, you aren't likely to make the same mistake again.

I did what the Alouettes' Ben Cahoon routinely does when he drops a pass. He goes directly back to the huddle, no whining, no demonstration, and he makes sure the next time he makes the catch.

Once I recognized this disease for what it is - one of the scariest lifetime experiences imaginable - I set about to do something positive. I may not be able to raise enough awareness to generate the money to find a cure, initially, but why not try? I may not be able to re-connect with all my old friends, the ones I had planned to get together with at some later date, but why not try? Recently I had lunch with three of my old CFL teammates I hadn't seen for 25 years. Perhaps you're not old enough to remember Mark Kosmos, Paul Brule and Jim Foley, but if you watched the CFL throughout the 1970s you would recognize them as stars in their own rights. We recounted all sorts of stories and lies, and confirmed the old saying: "The older you get, the better

you were."

Throughout the CFL season, I tried to focus positively on every situation and looked for opportunities everywhere. In order to live to the fullest, I think you need to look for these opportunities, even directly into the face of this disease. I now answer all my calls promptly, write thank you notes to every donor, smile at each person I interact with, talk positively, plan events I have put off until later and, in general, drink from a very large, half-full glass.

What's next? I plan to morph from a talker to a writer in expectation of losing my voice. I want to stay connected to the CFL in some way. Another book is in the cards, this one focusing on the role of the coach in the CFL, historically and strategically.

Most importantly, I want to make sure my family and I live life to the fullest, truly appreciating the opportunity we have together for a couple of years. My fate is already sealed, my destiny finite. My family and close friends will live on, and as part of my quest to ease their pain, and mine, of course, we're going to have the time of our lives.

If you would like to be part of Tony Proudfoot's crusade to further the battle against ALS, please donate to the Tony Proudfoot Fund at ALS-Quebec. Online: [sla-quebec.ca](http://sla-quebec.ca) and click on the link to the Tony Proudfoot Fund to make a donation. By telephone: (514) 725-2653.

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## RESEARCH COULD LEAD TO UNDERSTANDING OF MOTOR NEURON DEGENERATION

In an effort to leverage funds and increase the ALS profile among young researchers, the Tim E. Noël Fellowship in ALS Research was created in 2006 using money from the Tim Noël Endowment Fund. Sherif Elbasiouny is the 2007 recipient.

Elbasiouny believes ALS research is expanding but notes that attracting new and young investigators to the field is a challenge. He cites collaboration between well-established researchers and increased funding as two critical factors in the search for a cure or effective treatment for ALS.

Elbasiouny was inspired to pursue studies in rehabilitation engineering after witnessing the joy of a young amputee and his parents when the boy received his prosthesis. His interest in ALS research is an extension of his doctoral work, where he developed electrical stimulation-based techniques to suppress the level of spasticity (uncontrolled sustained contractions of muscles) after spinal cord injury.

"My desire to help ALS patients is my real motivation," he says.

Elbasiouny obtained his PhD in biomedical engineering with a focus on rehabilitation neuroscience from the University of Alberta in 2007. He has embarked on post-doctoral study at Northwestern University in Chicago, department of physiology under Dr. Charles Heckman. Elbasiouny's project is entitled "Ionic mechanisms underlying motoneuron degeneration in ALS."

When a substance over-stimulates nerve cells, it creates a toxic effect

called excitotoxicity, which may contribute to the degeneration of motor neurons in people with ALS. The voltage-gated channels of the motor neuron are thought to be a main cause of excitotoxicity. Voltage-gated sodium channels help generate electrical excitability, while voltage-gated calcium channels regulate muscle excitation and contraction. A component of the total sodium current, the Na persistent inward current (Na PIC), is elevated in the motor neurons of mice genetically modified to carry the mutant SOD1 enzyme, which is linked to an inherited form of ALS. When the calcium persistent inward current (Ca PIC) isn't buffered properly, the Na PIC current increases cell excitability, which could contribute to motor neuron degeneration in ALS.

"We expect to obtain a better understanding of how ionic currents contribute to motor neuron degeneration in ALS and what drug or electrical therapies could be used to help regulate their level of activation," says Elbasiouny. "The outcome of this work could lead to the development of new, effective therapies that would slow the progression of the disease and prolong life in ALS patients."

The main goals of the project are to investigate the ionic mechanisms causing the increased excitability of spinal motor neurons in ALS and to assess how drugs, electrical stimulation and neuromodulators (substances transmitted by a neuron that affect the activity of other neurons) affect motor neuron survival. Elbasiouny will use computer models



**Sherif Elbasiouny**

to try to verify Na PIC and Ca PIC as contributing factors in motor neuron excitability, and determine if these two ionic currents affect motor neuron cells before the onset of ALS symptoms.

Candidates for the Tim E. Noël Fellowship in ALS Research are eligible for \$55,000 in annual funding for up to three years. The fellowship is awarded through the CIHR INMHA fellowship competition. A peer review process determines the scientific merit of applications for funding.

### About Tim E. Noël

Tim E. Noël was the deputy governor of the Bank of Canada. Diagnosed with ALS in 1999, Noël continued working with the aid of his wheelchair and ventilator. He succumbed to ALS in July 2001. The funds from the endowment fund come from the golf tournaments organized by Noël's friends, who were inspired by his courageous battle with ALS. The Fund will continue to support a post-doctoral research fellowship in Noël's honor.

## ROULEAU HONORED BY QUEBEC GOVERNMENT



ALS Researcher Guy Rouleau, MD, PhD

**R**espected ALS researcher Guy Rouleau, MD, PhD, has another award to add to his collection.

Rouleau was named an Officer of the National Order of Quebec in a June 2007 ceremony. Rouleau is the Canada Research Chair in Genetics of the Nervous System and director of the Centre of the Study of Brain Diseases at the University of Montreal.

Honors are bestowed on citizens for outstanding achievements in most fields. Award recipients receive one of three designations: Knight, Officer or Grand Officer. Rouleau was one of 12 Quebecers awarded the designation of Officer.

"It's a great honor to be recognized for my contributions to science," says Rouleau. "But the greatest reward for my work would be to discover a cure for ALS."

Rouleau works with researchers from different backgrounds and fields on the design of new

drugs and treatments for diseases that affect the brain and the nervous system. His current research projects include identifying the genes responsible for simple and complex diseases and uncovering the function proteins affected by disease genes.

Additionally, Rouleau is carrying out an epidemiological analysis to determine if the environment is a factor in familial ALS (FALS). He has built a database of 250 people with FALS in Quebec City and Paris and hopes to increase this number to the thousands. Rouleau has also contributed to the mapping, isolation and characterization of many genes.

Rouleau's other accolades include Radio-Canada Scientist of the Year (1993), the CIHR Michael Smith Award (2000) and the Henry Friesen Award (2007).

The National Order of Quebec was instituted in 1984 by the National Assembly. It is one of the most prestigious honors in Quebec.

## NEW ALS CANADA RESEARCH PUBLICATIONS

### Research News Special Report

**T**he ALS Society of Canada has published a *Research News Special Report* highlighting key findings and discussions stemming from the 18<sup>th</sup> International Symposium on ALS/MND.

The annual event took place from December 1-3, 2007 at the Westin Harbour Castle, in Toronto, Ontario. Hundreds of international researchers and healthcare professionals came together to present, and debate, key innovations in their respective fields.

A Toronto first, this unique forum brought together 800 delegates from around the world, showcasing its global prominence as the largest international event of its kind - covering topics from cell biology and pathology to patient management and care.

For a copy of the *Research News Special Report* please visit [www.als.ca](http://www.als.ca). You may also contact the ALS Society of Canada at 1-800-267-4257 ext. 201 or e-mail us at [iwp@als.ca](mailto:iwp@als.ca) if you would like to receive a hard copy of the *Research News Special Report*. Copies are available in both English and French.

### Northern Neuron

For the latest information on Canadian research, we encourage you to take a look at *Northern Neuron*, a publication also produced by the ALS Society of Canada. *Northern Neuron* highlights research funded by the Society, to inform readers of the promising directions in neuromuscular research for treatments and a cure for ALS.

For a copy of *Northern Neuron* please visit [www.als.ca/northern\\_neuron](http://www.als.ca/northern_neuron). You may also contact the ALS Society of Canada at 1-800-267-4257 ext. 201 or e-mail us at [iwp@als.ca](mailto:iwp@als.ca) if you would like to receive a hard copy of the *Northern Neuron*. Copies are available in both English and French.

## ALS RESEARCH COMES OF AGE: ALS JOURNAL APPOINTS NEW EDITORIAL TEAM



**Denise Figlewicz, PhD, Director of Research at the ALS Society of Canada**

**T**he *ALS Journal*, the official publication of the World Federation of Neurology (WFN) Research Group on ALS/MND, is undergoing a mini-makeover, reflecting exciting change in the pace of ALS research. A new editor, neurologist Orla Hardiman

from Dublin, Ireland has been appointed. Together with associate editors Denise Figlewicz, PhD, director of research at the ALS Society of Canada and Reinhard Dengler, MD, professor of neurology and chair of the Department of Neurology at Hannover Medical School in Germany, and the new editorial board drawn from across the world of ALS clinicians and scientists, the *ALS Journal* will provide regular in-depth reviews of "hot

topics," in addition to encouraging rapid dissemination of peer reviewed clinical, translational and basic science research of high quality.

The WFN Research Group facilitates collaboration across borders defined by both geography and discipline. The *ALS Journal* is the only publication for this rapidly progressive neurodegenerative disease, and subscription is available as a benefit to members of the WFN Research Group on ALS/MND.

"Working together as a community of clinicians, scientists and care providers, we must continue to strive to make a dif-

ference in the lives of people with ALS. As the incoming editor, I, with the new editorial board, will do my best to attract and publish research that will help to make that difference a reality," says Hardiman.

For more information about the *ALS Journal*, and to become a subscriber, visit [www.informaworld.com/als](http://www.informaworld.com/als).

For more information about the World Federation of Neurology Research Group on ALS/MND, visit [www.wfnals.org](http://www.wfnals.org)

## MISCHIEVOUS MITOCHONDRIA

### Exploring the dysfunction and misdistribution of the cell's powerhouses

**C**hristine Vande Velde, PhD, a recent Neuromuscular Research Partnership grant recipient, is in the preliminary stages of unraveling the many mechanisms of motor neuron degeneration in ALS. Over the next three years, Vande Velde and her research group aim to focus their attention on evaluating mitochondria, the powerhouses of the cell, and their function in mouse models in a study entitled "Identification of the mechanisms of motor neuron degeneration in ALS."

It is believed that an early and central feature of ALS is the irregular behavior of the mitochondria, which ultimately

affects the livelihood of motor neurons. These motor neurons are an important link in the nervous system, as they connect signals from the brain to the voluntary muscles throughout the body. By exploring this cause of motor neuron degeneration, Vande Velde hopes to shed light on another dimension of the process; this is part of the groundwork needed by the research community to develop effective therapies in the battle against ALS.

Under the direction of the late Dr. Arnold Greenberg at the Manitoba Institute of Cell Biology and the department of biochemistry and medical

genetics, Vande Velde studied mitochondrial-mediated mechanisms of programmed cell death in cancer for her PhD. Towards the end of her doctorate, Vande Velde viewed neurodegeneration as a result of the premature death of certain cells, and as such opted to pursue this field of interest. Wanting to create and work with mouse models, Vande Velde surveyed the major neurodegenerative diseases for experiments in which mouse models had been used and programmed cell death had been explored. ALS was her answer.

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## MISCHIEVOUS MITOCHONDRIA Continued from Page 8

In reviewing ALS literature, Vande Velde was drawn to fellow researcher Don Cleveland, PhD, a University of California, San Diego, professor of medicine, neuroscience and cellular and molecular medicine, as well as a member of the Ludwig Institute for Cancer Research and a member of the U.S. National Academy of Science. After much persistence, Cleveland, a leader in ALS research, hired Vande Velde to be a member of his team, a position she held for six years.

The desire to pursue a career in ALS research always seemed to conflict with the hope of returning home to Canada, since at the time, ALS funding was nominal in Canada. "With the current funding situation - Canada is just better right now," states Vande Velde. It wasn't long before Vande Velde happened upon an opportunity to work with Dr. Guy Rouleau, an internationally renowned ALS geneticist, at the Centre de recherche de CHUM and Université de Montréal, an offer she could not pass up.

The identification of mutation in a pro-

tein called copper/zinc superoxide dismutase (SOD1) in some cases of familial ALS led to the creation of laboratory models - particularly transgenic mice - in which motor neuron degeneration resulted from one known cause of human ALS. And while the SOD1 model has been extremely useful in studying ALS, new models are needed and these can come only from new advances in genetics, Rouleau's specialty, and an area Vande Velde feels needs great attention. "Much has been based on the SOD1 models, which are very useful, but it would be nice to be able to evaluate some mechanisms and therapies in another model - and thus give one greater confidence that this is really the way it (ALS) works."

Vande Velde is also excited about the upcoming trial of antisense oligonucleotide treatments in ALS patients, a study she has seen progress over the last six years while in Cleveland's lab. Antisense oligonucleotide treatments use short strings of nucleotides (subunits of DNA) to block the process of gene expression, a treatment that will be particularly helpful in blocking the mutated SOD1 gene which causes some forms of familial ALS.

Her main focus continues to lie in identifying the cause of this devastating disease.

"Once we know **Christine Vande Velde, PhD** the cause (or causes), then we can make directed advances in therapy development. At present, many efforts focused on pharmaceutical-based treatments have not been successful when used in patients. In some cases, the reason is because we just need to learn more about what we're trying to fix."

Being an active participant in ALS walks and research day events in San Diego, Vande Velde plans on getting involved with the local ALS Society in Quebec. "Every researcher, at all levels, should meet patients and their families at least once a year - it is a very humbling experience and quickly reminds one of why we go to the lab every day."



## STUDY REPORTS THAT LITHIUM DELAYS PROGRESSION OF ALS

Italian researchers recently published a ground-breaking study that indicated that the drug lithium delayed ALS progression in a small group of patients (44 in total - 20 female and 24 male). In their paper published in the American journal *Proceedings of the National Academy of Sciences*, the authors state that all subjects treated with lithium, in combination with riluzole, were alive at the end of the follow up (15 months), and their quality of life was not modified. By contrast, 29 per cent of the patients receiving riluzole alone died during the study.

Sixteen trial participants were chosen to receive 50 mg a day of riluzole, in addition to two daily doses of 150 mg of lithium carbonate. If necessary, doses were adjusted up to 450 mg a day during the study to maintain targeted blood levels of 0.4-0.8 mEq/liter. The remaining 28 participants received riluzole only.

Denise Figlewicz, PhD, says that, "The recently published data serve as the impetus for new research and new treatment strategies. The ALS Society of Canada is working closely with the

Canadian ALS research community to quickly follow up on these exciting results and planning is underway for nationwide clinical studies of lithium as a potential treatment for ALS. This is the first promising opportunity which has come along in many years." However, Figlewicz cautions, "Because lithium is a potentially toxic drug, it must be taken under a doctor's supervision with frequent monitoring of blood levels." Common side effects include muscle tremors, twitching, kidney damage, and seizures.

## DOCTORAL AWARD RECIPIENTS CHOSEN FOR PASSION AND INNOVATION

Attracting bright, young investigators to ALS research isn't an easy task, but through the funding of generous research awards, promising scientists are joining the fight against this devastating disease.

To encourage cutting edge research, the ALS Society of Canada - CIHR INHMA Doctoral Research Award was created to fund PhD students conducting ALS-related research for up to three years. This year's recipients are Xiaoyang Shan and David Gosselin.

Xiaoyang Shan obtained his MD from Guangxi Medical University in China and moved to Canada to pursue graduate studies. He was introduced to neurodegenerative diseases by respected ALS researcher Dr. Charles Krieger while earning his M.Sc. at Simon Fraser University (SFU). Shan is currently a PhD candidate in the department of molecular biology and biochemistry at SFU under the supervision of Dr. David Vocadlo. His research project is entitled "The role of O-glycosylation in a mouse model of ALS."

Shan notes there is significant evidence that phosphate groups are attaching to proteins in the nervous systems of people with ALS. Because phosphate groups regulate protein action, having too many can interfere with the normal function of proteins. Neurofilaments, proteins associated with the progression of ALS, are known to have excess phosphate in the pathology of ALS and mutant SOD1 mouse models.

Sugar groups may also attach to some of the same sites as the phos-

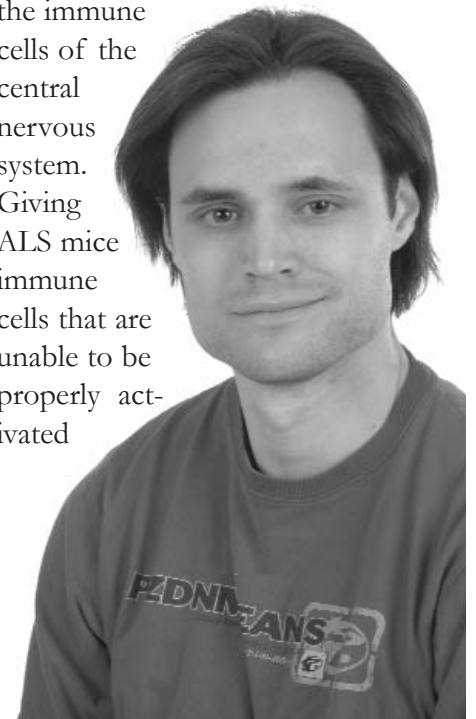
phate groups. Scientists speculate that if the sugars can attach to proteins in place of phosphates, the function of some proteins may be improved. Shan believes that achieving a balance between the sugars and phosphates will prevent the accumulation of neurofilaments. He focuses on mouse models of ALS, where he examines the effects of sugar-increasing compounds on various proteins. Initial results have indicated a significant increase in short-term protein levels using one of the compounds. He will next examine if the attachment of phosphates on disease-associated proteins is decreased. This will be followed by a long-term trial to evaluate the effects of the compounds on the progress of ALS. Shan hopes the results will lead to a cure or effective treatment for ALS.

"ALS is a devastating disease affecting thousands of Canadians beyond the approximately 2,500 to 3,000 living with the disease. Finding a cure through research would not only benefit people with ALS, but their families and our society, too," says Shan.

After obtaining his M.Sc. in physiology and endocrinology at l'Université Laval, David Gosselin is continuing his studies in that department as a PhD candidate under the supervision of Dr. Serge Rivest. His research project is entitled "Increasing microglial expression of CCR2 and IGF-1 through genetic engineering of hematopoietic stem cells (HSC) for the treatment of ALS."

According to Gosselin, recent studies

indicate that mutant SOD1 can activate microglia, the immune cells of the central nervous system. Giving ALS mice immune cells that are unable to be properly activated

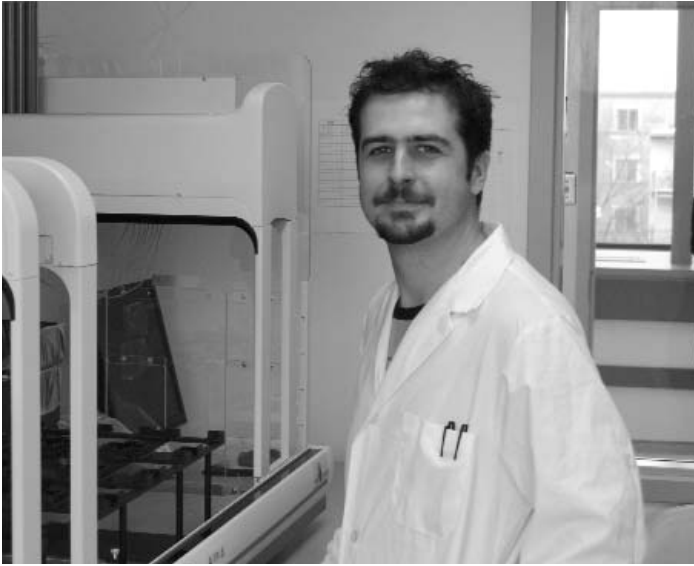


David Gosselin

because of expression of mutant SOD1 accelerates the progression of the disease. The mice will be treated with insulin-like growth factor (IGF-1), which is reported to prolong the lives of SOD1 mice and delay disease progression. IGF-1 will be transmitted to the central nervous system via stem cells isolated from the blood or bone marrow. The cells will also contain CCR2, a chemokine receptor that can improve the ability of immune cells to reach the site of the disease. Chemokine receptors are a small area of protein on the surface of a cell to which external chemical bodies attach. CCR2 is thought to be of central importance to inflammatory diseases and will help IGF-1 attach to the immune cells.

Continued on Page 11

## RESEARCHERS IDENTIFY A GENE RESPONSIBLE FOR ALS



**Edor Kabashi, PhD**

A team of Canadian and French researchers has identified a novel gene responsible for a significant fraction of sporadic ALS cases.

Published March 30<sup>th</sup> online in *Nature Genetics*, the study on 200 human subjects with ALS was led by Guy Rouleau, MD, PhD; Edor Kabashi, PhD; and, Paul Valdmanis of the Research Centre of the Centre hospitalier de l'Université de Montréal. The team identified several genetic mutations in the TDP-43 gene by studying ALS patients from France and Quebec. They established TDP-43 as the gene responsible for up to five percent of the ALS patients.

### DOCTORAL AWARD RECIPIENTS CHOSEN FOR PASSION AND INNOVATION

Continued from Page 10

Behavioral tests will be performed to assess recovery, and the central nervous systems of the mice

models will be analyzed using markers of inflammation, neurodegeneration and repair. Gosselin believes this proposed therapy will achieve significant results in mouse models of ALS within three or four years and could even-

The breakthrough is the result of teamwork with peers from the Waterloo and Laval universities in Canada and the Fédération des maladies du système nerveux and the Institute of Biology (Unité de Neurologie Comportementale et Dégénérative) in France.

TDP-43's normal function is to bind

and splice RNA. Two years ago, a team from the University of Pennsylvania discovered TDP-43 in abnormal protein clumps, referred to as aggregates, in motor neurons of ALS patients. However, it was not certain whether TDP-43 causes motor neuron disease or is just a pathological marker.

"The identification of additional mutations

in TDP-43 in other ALS patients will confirm that this gene is a prominent cause of this type of disorder," says Rouleau, director of the Sainte-Justine Hospital Research Centre. "Animal models over-expressing the mutations identified in this study will provide crucial insight into how TDP-43 aggregate and ultimately kill motor neurons."

"This discovery is a step towards the development of therapies for people suffering from this terrible disease and possibly other neurodegenerative diseases," explains Kabashi.



**Paul Valdmanis**

ually become a therapeutic treatment for people with ALS.

"I think great progress will be made over the next decade," says Gosselin. "Researchers are moving beyond studying ALS from

a neuronal perspective. We now know enough to realistically attempt to genetically engineer the immune system, which could benefit people living with the disease."

## MYRNA MOORE: A CARING HAND

On June 5, 2007, Myrna Moore, clinical co-ordinator of the Sunnybrook Health Sciences ALS/Neuromuscular Clinic, was awarded a *Schulich Award for Clinical and Nursing Excellence* at the 5<sup>th</sup> annual award ceremony in Toronto, Ontario.

This is not the first award Moore has received for her contributions to the ALS community. In 1997, she was awarded the *Myra Rosenfeld Volunteer Award* for her commendable leadership and volunteerism by the ALS Society of Canada.

The Schulich Awards, funded by Dr. Seymour Schulich, recognize the dedication and commitment of health-care professionals at Sunnybrook who embody the hospital's values of excellence, collaboration, accountability, respect and empowerment. Nominations are made by staff, patients and family members who believe the individual to be a role model to others - demonstrating exemplary precision, sensitivity and attention to detail in patient care.

In addition to her job as clinic co-ordinator, Moore also works closely with the ALS Society of Ontario, where she has chaired eight annual conferences titled ALS: Strategies for Quality Care Days. Moore has also published articles on caregiving in numerous publications.

## FIRST BETTY NORMAN CLINICAL FELLOWSHIP IN ALS RESEARCH AWARDED

The ALS Society of Canada is pleased to announce Kerri Schellenberg, MD, has been awarded the first Betty Norman Clinical Fellowship in ALS Research. Schellenberg will be studying under Dr. Wendy Johnston, a neurologist and associate professor of neurology at the University of Alberta.

The two-year fellowship emphasizes ALS clinical care and research. It focuses on three areas: clinical expertise and leadership, teaching and research. Schellenberg will train in the ALS clinical program and the electromyography laboratory at the University of Alberta.

"This is an excellent opportunity for a young physician," says Johnston. "We're delighted to welcome Dr. Schellenberg to our clinic. Her training and enthusiasm for the profession will take her far."

Schellenberg graduated from the University of Saskatchewan's College of Medicine with great distinction and completed a residency program

in neurology at the University of Alberta. Schellenberg has co-written three articles, published in the prestigious *American Journal of Physical Medicine and Rehabilitation*, *Canadian Journal of Psychiatry and Parkehurst Exchange*.

"Having spent the last six years completing my residency here, I know I will continue to receive high-calibre instruction from Dr. Johnston and her colleagues," says Schellenberg. "I'm looking forward to learning how to provide quality care to people suffering the devastating effects of ALS."

The University of Alberta's ALS multidisciplinary clinic program was established in 2001. The majority of Schellenberg's training will occur at the University of Alberta. She will also participate in monthly clinics at two outreach sites, Misericordia Hospital and Glenrose Rehabilitation Hospital, both in Edmonton.

"There is a serious shortage of ALS specialists in Canada. This fellowship will help

ensure doctors are adequately trained to handle the special needs of people with ALS," says Denise Figlewicz, PhD, director of research at the ALS Society of Canada.

The fellowship is named for Betty Norman, an active 58-year-old Calgarian diagnosed with ALS in August of 1996. Despite her diagnosis, Norman aspired to make a difference. Betty, along with family and friends were frustrated by the lack of ALS awareness and the small amount of research being done at the time. In response to these issues, Norman, her family and friends organized the first Betty's Run/Walk for ALS in June 1997 just two weeks before Betty passed away. Betty's Run for ALS celebrates, promotes and channels hope for those affected with ALS, their families and their friends. The event has raised more than \$2.5 million for ALS client services, equipment and research since its inception.



## CRITICAL ILLNESS INSURANCE - By: Mark Halpern, CFP, FMA - Founder of [www.illnessprotection.com](http://www.illnessprotection.com)

**M**embers of the ALS community know that a critical illness is a life-altering experience.

Healthy family members, friends and caregivers need to know about Critical Illness Insurance (CI) and why it's so important to get CI while you are healthy.

Recent advances in medical science and improved lifestyles give all of us a far greater likelihood of surviving a critical illness, but financial survival is not assured.

What would happen if you woke up tomorrow in the hospital after experiencing even a mild heart attack? Your doctor might simply recommend a change of diet and more frequent exercise. But what if you had to modify your lifestyle even further - such as being forced into early retirement or trading in your old job for a new one that is less stressful and less rewarding?

The financial and emotional impact on a family is devastating. In addition to being forced to cope with dramatic lifestyle changes, you quickly realize that the mortgage and other monthly living expenses still need to be paid.

To compound the problems, the incredible strain on our medical system makes wait times for surgery, treatments and other procedures common place - the headlines remind us daily of a situation getting worse. Who can be sure that treatment will be available if needed? Having financial resources means having more choices.

CI pays a lump sum, tax free, 30 days after the diagnosis of a covered condition. (See list)

Coverage can range from \$25,000 to \$2,000,000. There are no strings

attached on how the money is used.

### YOU CAN:

- Pay off debts or mortgages
- Stop working and concentrate on recovery
- Supplement income
- Pay for medical treatments not offered in Canada
- Get quicker treatment outside of Canada
- Take an extended vacation to improve recovery
- Make alterations to your home that may be necessary because of your new condition

### COVERED CONDITIONS:

- Cancer
- Heart Attack
- Bypass Surgery
- Stroke
- Multiple Sclerosis
- Coronary Angioplasty
- Heart Valve Replacement
- Aortic Surgery
- Parkinson's Disease
- Alzheimer's Disease
- **Motor Neuron Disease (ALS)**
- Benign Brain Tumor
- Coma
- Blindness
- Deafness
- Kidney Failure
- Major Organ Transplant
- Major Organ Transplant Waiting List
- Paralysis
- Loss of Limbs
- Occupational HIV Injury
- Severe Burns
- Loss of Speech

The statistics:

- One in three Canadians will get

cancer...one in nine women will get breast cancer...one in eight men will get prostate cancer

• 75,000

Canadians have a heart attack each year...half are under age 65

• 40,000 - 50,000 Canadians suffer a stroke each year...60 per cent suffer a long-term disability

• Early detection is getting better and survival rates are increasing

• Five-year survival rate for men with prostate cancer is 87 per cent and for women with breast cancer it's 82 per cent

• Eighty per cent of heart attack victims survive

• Eighty-five per cent of stroke victims survive

If you are fortunate enough to stay healthy and never make a claim on your CI, your premiums can be returned to you, in full.

If you die of any reason while the policy is in force, and you did not receive a CI benefit while you were alive, all the premiums will be refunded to your family/estate in full.

The policies are issued by the largest insurance companies in Canada such as Manulife, Canada Life, RBC, Sunlife and Great West Life.

All of us are in a similar situation. We are either in (or starting) our prime income earning years, we are taking on mortgages, trying to save for retirement, starting families, etc.

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## ADAM CHOLMONDELEY - *Junior Citizen of the Year*



Left to right: Ross and Adam Cholmondeley

**T**welve-year old Adam Cholmondeley is one of a select group of youth presented with a 2007 Ontario Junior Citizen of the Year Award.

Adam, a student at Module Vanier Public School in Kingston, Ontario, was nominated for the award by his aunt, Jane Anderson, who felt Adam had made an exceptional contribution to his community through his commitment for the fight against ALS.

"People are interested to

know about such a young person being so motivated and articulate," says Anderson.

Adam was seven when he was confronted with the news that his father had been diagnosed with ALS. At the time, Adam's dad, Ross, was still able to walk and play road hockey with him. However, as years passed, ALS has left Ross limited to playing goalie, in a wheelchair.

The youngest of three children, Adam decided that he wanted to do something to find a cure

for the disease that was robbing his dad's life.

At age 11, it became increasingly apparent that the only thing that could help him figure out the cure to his father's disease was money. In 2005, he began collecting money for ALS research. He has since been involved with collecting pledges, partaking in the local ALS WALKs, launching a fundraising walk at his school, developing a web site, and raising ALS awareness in a country-wide advertising campaign.

In 2007, Adam's efforts were recognized as he was the top individual fundraiser for the WALK for ALS in Kingston, raising a total of \$5,377.

"He desperately wants to find a cure for ALS, not only for his dad, but for all the people who suffer from the disease," says Anderson.

While Adam enjoys playing soccer and participating in other activities for children his age, Adam also plays another important role at home, he takes care of his father. Neither of which has affected his grades - a school project on his grandfather's jewellery business won him the Mayor's Award and the Kingston Chamber of Commerce Award at the Regional Heritage Fair in 2006.

Since 1981, the Ontario Junior Citizen of the Year Awards Program has recognized the contributions of outstanding youth who are making a difference in their communities.

"Sometimes it is not how much money is raised for a cause that matters - it is the effort, drive and determination of someone at a very young age that inspires, impresses and gives us all hope," says Anderson.

### CRITICAL ILLNESS INSURANCE

Continued from Page 13

What if a critical illness hit you and you had to take a "time-out?" This product can provide the financial safety net you and your family needs to let you concentrate on recovery.

Our advisors across Canada are available to help you and your family with life insurance, critical-illness, disability, long-term insurance and estate plan-

ning.

Mark Halpern, CFP, FMA, has been an independent insurance advisor since 1991. Halpern was recognized by Manulife Financial in 2005 and 2006 as their number one living benefits advisor.

For more information please visit:  
[www.illnessPROTECTION.com](http://www.illnessPROTECTION.com)

### Disclaimer:

In this publication, we report on current research, new technological devices and other products and services. ALS Canada neither endorses or recommends these products and does not assume responsibility for the information contained in this newsletter.



## TECHNOLOGY

### COMMUNICATE BETTER WITH NEXTUP TALKER

NextUp.com has unraveled a new text-to-speech application, NextUp Talker, specifically designed for individuals who have temporarily, or permanently, lost their voice.

Like other speech synthesis programs, written input is converted to spoken output automatically through the generation of artificial speech. With the use of natural, human sounding voices, NextUp Talker makes communication easy for those with vocal impairments.

NextUp Talker can be purchased at [www.talkforme.com](http://www.talkforme.com) for \$99.95 (U.S. funds). For more information please visit [www.talkforme.com/products.html](http://www.talkforme.com/products.html)

### NEW SOFTWARE ALLOWS SPEECH DISABLED TO TOUCH AND TALK

The Touch and Talk Speech Communication and Therapy Software Package help patients suffering from a variety of speech-related disabilities, including ALS. Patients can type, click, or point to an alphabetical word or phrase list on a screen to build sentences. The computer will then translate the selected dialogue into actual speech. Touch and Talk's built-in text-to-speech engine will narrate the chosen phrases in the voice of a man or women for more personalized communication. Other features include 911 alert, medication reminder, alarms and a caregiver's log.

Touch and Talk 4.0 is also equipped with a speech-enabled instant mes-

saging feature. This feature facilitates unlimited communication between patients and family members or caregivers and requires a simple internet connection.

The program is currently available in English. The Touch and Talk 4.0 is compatible with Windows-based PCs and can also be used on laptops and touch screen computers.

The Touch and Talk 4.0 may be purchased online for less than \$100. For more information, visit [www.TouchnTalk.com](http://www.TouchnTalk.com)

### NEW DEVICE LENDS A VOICE TO PEOPLE WITH ALS

Voice-banking enables people with ALS to record their voices on computers and play them back when they can no longer speak. A new system offers another option for saving voice recordings with ease and precision.

The ModelTalker Speech Synthesis System's voice-banking technology uses representative segments of a person's recorded speech to create a unique synthetic voice, which can be used on a speech communication device.

"We take natural speech that's been recorded and chop it into small pieces that we mix and match. We put the pieces together in a variety of ways to produce utterances that sound like they're from the speaker who did the original recordings," says H. Timothy Bunnell, the project's principal investigator and head of the speech research lab at the duPont Hospital for Children in Wilmington, Delaware.

Although the software is still under development, Bunnell says it's been used by a number of people with ALS. It can be downloaded at no cost. The software requires a Windows-based PC with audio capabilities and a head-mounted microphone.

ModelTalker can also be used as a stand-alone text-to-speech application that lets you type text into a window on an AAC device or computer, then hear it spoken using your synthetic voice.

ModelTalker is still experimental and offers no guarantees. Bunnell cautions users to have realistic expectations about their new synthetic voice, because it won't sound exactly like their real voice.

Visit the ModelTalker web site, [www.modeltalker.com](http://www.modeltalker.com), to hear sample voices, most of which come from people with ALS.

### MANY HANDS HELP MAKE A DIFFERENCE

Imagine a job that doesn't pay, involves heavy lifting and requires you to always be on duty. This is the life of a primary caregiver.

The primary caregiver of a person with ALS is usually a close relative, such as a spouse or child. They face emotional struggles, financial and employment issues, as well as physical strain. While some caregivers are relieved by hired help, this option is not always available.

To help eliminate these common problems, Lotsa Helping Hands, a free online caregiving co-ordination

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## MANY HANDS HELP MAKE A DIFFERENCE

service designed for family caregivers, has upgraded its features. The new community communication tools provide greater support during times of medical crisis, caregiver exhaustion, or when caring for elderly parents. The web site is designed to easily co-ordinate the help offered to a family caregiver by friends and loved ones and to help stay better informed through options such as status updates, photo galleries and message boards.

"Our private communities help alleviate the daily pressures facing caregivers by allowing those around them to jump in and help out with the daily activities that often become a challenge during times of medical crisis or caregiver exhaustion," says Hal Chapel, CEO of the Massachusetts-based Lotsa Helping Hands.

A lead co-ordinator sets up the personalized, password-protected site and invites friends, family, colleagues and neighbors to join the community. The community plays an active role in providing support to both the patient and

the primary caregiver. The enhanced system builds on the group calendar coordination feature and allows coordinators to create, manage and customize new community sections based on their particular needs.

Caregiver assistants sign up for various tasks, including meal delivery, transportation to medical appointments, housecleaning, babysitting, carpooling and visitations. A calendar tracks each person's tasks to keep helpers organized.

Communities can be created online at [www.lotsahelpinghands.com](http://www.lotsahelpinghands.com).

## SAVE THESE DATES

**The 17th International Congress on Palliative Care** will be held from September 23-26, 2008, at the Palais des Congrès in Montréal.

Since its beginnings more than 30 years ago, this biennial congress continues to promote the exchange of leading-edge ideas, practices and technologies available in the rapidly growing field of palliative care - care for the terminally ill.

For more information and to register please visit [www.pal2008.com](http://www.pal2008.com) or call 450-292-3456 ext. 227.

### 2008 ALS Society of Canada

**Research Forum** - The fourth annual research forum at the Sheraton Gateway Hotel in Toronto from May 3-5, 2008. The purpose of the forum is to promote discussion among members of the Canadian ALS research community to better understand the underlying biology of ALS, develop effective therapies and to improve the quality of care for ALS patients and their families, with a focus on how the ALS Society of Canada can best facilitate these efforts.

For more information contact Enzo Raponi, senior manager projects and events at the ALS Society of Canada at 1-800-267-4257 ext. 205, or [er@als.ca](mailto:er@als.ca).

**People in Motion 2008** - The 19th annual People in Motion will be held at the Queen Elizabeth Building, Exhibition Place in Toronto on June 5 and 6, 2008.

Admission is free, and persons with disabilities, seniors with special needs, family members and friends, and professionals working in related areas are all encouraged to attend.

Featuring more than 120 exhibits, such as mobility aids, adapted vehicles, home health-care products, and employment opportunities, this event makes it easier for consumers and professionals to see and compare new and existing products and services on the market.

For more information call 1-877-745-6555 or visit [www.people-in-motion.com](http://www.people-in-motion.com)

**Symposium on ALS** - will be held in conjunction with the 43<sup>rd</sup> annual Canadian Neurological Sciences Federation Congress on June 17, at The Fairmount Empress Victoria & the Victoria Conference Centre in Victoria, B.C. The purpose of the symposium is to provide up-to-date information about treatment and symptom management based on current research. The confer-

ence is aimed at health-care professionals and people with ALS, their families and caregivers. For more information and to register please contact Enzo Raponi, ALS Canada, 1-800-267-4257 ext. 205 or [er@als.ca](mailto:er@als.ca)

### 5th Annual ALS Client Services

**Conference** - will be held June 17 and 18 in Victoria, B.C. The conference is an opportunity to learn about programs and services offered across the country, clinical care issues, practice management issues, clinic-society collaborations, and to build stronger peer relationships. The conference will be of interest to ALS clinic and society staff involved in client/support services. For more information visit [www.als.ca/2008clientserviceconference](http://www.als.ca/2008clientserviceconference).

## TAX SAVINGS THROUGH THE DONATION OF BCE SHARES

**B**CE, Bell Canada Enterprises is a public company that is pending privatization. This means that shareholders will need to sell their shares. BCE stock is one of the most widely held in the country and many people have held shares for years as part of their investment portfolio. Upon selling, holders will likely benefit from a significant capital gain (increase in value of the shares since purchase), but will also face

some significant tax liabilities as 50 per cent of the gain becomes part of your taxable income for the year.

One option to consider is to donate a portion of your shares to the ALS Society of Canada. Recent changes to the Income Tax Act mean that you do not pay any capital gains tax when publicly traded securities are donated to a registered charity such as the ALS Society of Canada.

Depending on the number

of shares you hold and their purchase price, you could be in the position to make a significant investment in ALS research and receive a tax credit. This is true for all publicly traded securities, not just BCE. Please note that the benefit is only possible if you transfer the shares. Selling the stock and donating the proceeds drastically reduces your possible tax credit and activates the capital gains component.

While the ALS Society of Canada encourages you to consult your financial advisors before making any significant charitable gift, we are happy to discuss your situation and illustrate how you and ALS Canada would benefit from such a contribution.

For more information, contact Scott Fortnum, vice-president of development, ALS Society of Canada, at 1-800-267-4257 ext. 228 or by e-mail at [sf@als.ca](mailto:sf@als.ca)

## 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

David Cameron, President & CEO .....	dc@als.ca .....	ext. 206
Enzo Raponi, Senior Manager Projects and Events .....	er@als.ca .....	ext. 205
R. Scott Fortnum, Vice-President Development .....	sf@als.ca .....	ext. 228
Denise Figlewicz, Director of Research .....	daf@als.ca .....	ext. 202
Darija Ilic, Development Manager .....	di@als.ca .....	ext. 203
Claudia Daniel, Development Co-ordinator .....	cmd@als.ca .....	ext. 204
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Karen Hunter, Director of Finance .....	kh@als.ca .....	ext. 207
Indra Patterson, Administrative Assistant .....	iwp@als.ca .....	ext. 201
Andrew Romano, Special Events Co-ordinator .....	ar@als.ca .....	ext. 210

## BROTHERS BIKING ACROSS CANADA IN MEMORY OF FATHER

While most people use their summers for barbecues and beach days, the Teeter family will be pedalling their bicycles across Canada for ALS.

The Teeter brothers - Michael, Aaron and Adam - lost their father Steve to ALS in 1994.

The Brothers Bike for ALS is their dream to raise funds and awareness about the disease that took their father.

"As a family who has lost a loved one to ALS, our hope is to encourage others by sharing our story," says Adam.

The brothers, along with their wives Juliet, Amy and Heather, will be on the road from May 28 to August 2, 2008. Adam and Aaron, who live in London and Hamilton, Ontario, respectively, will join Michael in Langley, British Columbia to kick off their tour. Their goal is to raise \$52,000 as they bike through many communities from coast to coast.

"We want this fundraiser to celebrate our father's life and give hope to those living with this terrible disease," says Michael.

"Our father's life serves as a reminder that we can't control the end of our days. What we can control is the quality of the life we live in the circumstances that we find ourselves. We decided to take control of our grief by organizing this fundraiser," says Aaron.

For information about their tour or to donate, please visit [www.als.ca/events/mydonate.aspx?fid=994](http://www.als.ca/events/mydonate.aspx?fid=994). The Teeter brothers also have their own site, [www.brothersbike4als.googlepages.com](http://www.brothersbike4als.googlepages.com)

## 2008 WALK SEASON LAUNCH

Continued from Page 1

Since the Walk began in 2001, approximately \$11 million has been raised.

"Support from people and organizations across Canada are essential to the success of the Walk," says Zack Werner, national chair and spokesperson for the WALK for ALS. "I appreciate the efforts of all WALK for ALS participants, volunteers and sponsors. Their commitment makes the WALK for ALS successful. I'm inspired by their dedication and enthusiasm."

Werner, the music industry veteran known for his role as a judge on Canadian Idol, has been affiliated with the Walk since 2006. He lost his father, Leonard, to ALS in 1997 and knows firsthand the devastating effects ALS has on individuals and their families.

"The effects of ALS are not just felt by the person living with the disease - they're felt by the whole family,"

says David Cameron, president and CEO, ALS Society of Canada.

"Funds raised at the Walks help Canadians affected by ALS and provide hope for a future without this disease."

The proceeds support provincial societies to fund client services such as equipment assistance, home visits and peer support groups and fund Canadian research in hope of finding a cure for the disease.

"We're confident that the 2008 WALK for ALS will be our most successful yet," says Cameron. "This event has seen tremendous growth, and with our new web site attracting a lot of attention, we have big expectations for 2008."

The new web site, [www.walkforals.ca](http://www.walkforals.ca), allows participants to register online and set up their own web site to share stories, photos and fundraising goals. The new design makes it easier for participants to view team information and collect

donations both on and offline.

"We want participants to get excited about the Walk. We want them to feel good about their efforts. We want them to know they're making a difference in the lives of people with ALS," says Scott Fortnum, vice-president of development, ALS Society of Canada.

For more information about ALS Canada's WALK for ALS and other events, including dates and locations, visit the new fundraising community site, [www.walkforals.ca](http://www.walkforals.ca).

The 2008 Walks will be taking place in the following cities: (Next Page)



**Join A Walk In Your Local Community**

**ALBERTA**

Cold Lake	Lakeland Lutheran Church	June 21
Edmonton	Hawrelak Park	June 14
Grande Prairie	Muskosepi Park	June 7
Lethbridge	Henderson Park	June 7
Lloydminster	Bud Miller Park	Sept. 13
Manning	Lion's Club Park	June 14
Medicine Hat	Strathcona Island Park	June 7
Red Deer	Little Chief Park	June 14

**BRITISH COLUMBIA**

Fraser Valley	Mill Lake Park	June 14
Mid Island	City Hall Malaspina Complex	June 8
Okanagan	Waterfront Park, Kelowna	June 21
Okeover	The Laughing Oyster Restaurant	April 5
Prince George	Masich Stadium	June 22
Richmond	Garry Point Park, Steveston	June 21
Surrey	Bear Creek Park	June 14
Victoria	University of Victoria, Parking Lot #6	Sept. 21
West Kootenay	Lakeside Rotary Park, Nelson	June 1

**MANITOBA**

Whitemouth	Whitemouth School	May 23
Winnipeg	Assiniboine Park, Central Picnic Area	June 14

**NEW BRUNSWICK**

Bathurst	TBD	June 7
Fredericton	Wilmont Park	June 7
Miramichi	TBD	June 7
Moncton	TBD	June 7
Saint John	Market Square Boardwalk	June 7

**NEWFOUNDLAND**

Clarenville	Nancy Stanford's School of Dance	June 8
Corner Brook	Bennett Hall on West Street	June 8
Georgetown	Longpond	June 8
Labrador City/Wabush	Royal Canadian Legion	June 8
Marystown	TBA	June 8
St. John's	Mews Community Centre Mundy Pond	June 8
Stephenville	Knights of Columbus Building	June 8

**NOVA SCOTIA**

Cape Breton - CBRM	Knights of Columbus Branch 3209	June 7
Halifax	Halifax Armouries	June 7
Truro	Truro Superstore	June 7

**ONTARIO**

Alliston	Alliston Christian Reformed Church	June 7
Barrie	Springwater Provincial Park	June 21
Brampton	Jim Archdekin Recreation Centre	June 7
Cobourg	Victoria Park	Apr. 27
Cornwall	St. Lawrence College	June 7
Durham	Port Perry Fairgrounds	June 21
Halton	Bronte Creek Provincial Park	May 19
Hamilton	Bayfront Park	June 7
Kingston	Lake Ontario Park	June 28
Kitchener/Waterloo	RIM Park	June 21
London	Springbank Park	Sept. 27
Mississauga	J.C. Saddington Park	June 7
Newmarket	Fairy Lake Park	June 22
Niagara Falls	Chippawa Lions Park	June 28
Ottawa	Lansdowne Park	June 7
Parry Sound/Muskoka	Parry Sound Town Beach	May 24
Stratford	Upper Queens Park	June 14
Sudbury	TBD	June 7
Thunder Bay	Slovak Legion	Sept. 27
Timmins	Gillies Lake Conservation Area	June 7
Toronto	Wilket Creek Park	June 7
Wingham	Riverside Park	June 21

**PRINCE EDWARD ISLAND**

Oyster Bed Bridge	Raceway Park	June 14
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**QUEBEC**

Clermont	Parcours des Berges	Sept. 7
Montréal	Parc Maisonneuve	Sept. 20

**SASKATCHEWAN**

Regina	Wascana Rehab Centre	June 7
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Most people diagnosed with ALS lose the ability to use their legs in the first two years of the disease...

“What Would You Do, While You Still Could?”

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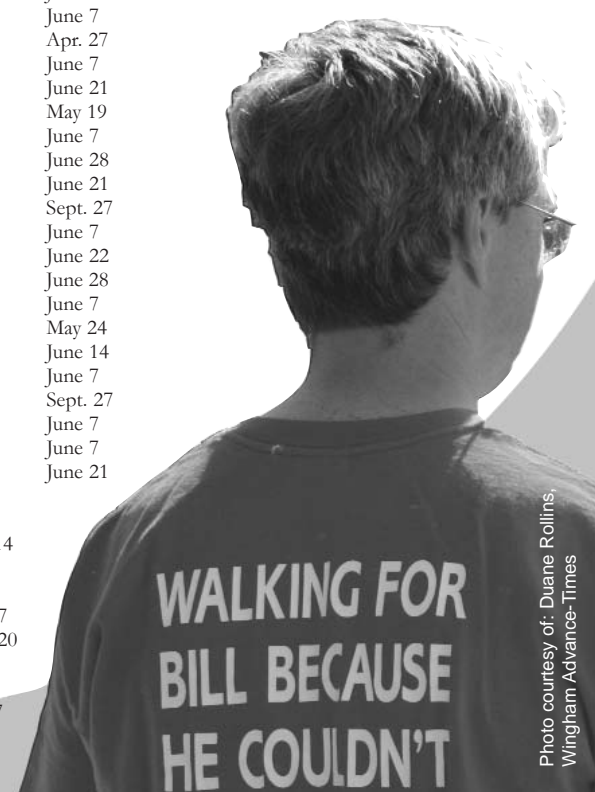


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