Zack Werner is a prominent figure in the Canadian music industry, working as an artist, producer, entertainment lawyer and manager. President of Toronto-based Venus Management and Venus Records, Werner is best known for his role as a judge in popular CTV series Canadian Idol.

"I am very proud to be associated with this event and to be able to be a part of finding a cure for this devastating disease," says Werner. "I have seen firsthand what this disease does to a person and we must find a cure."

The ALS Society of Canada is thrilled to have Werner back in the role of national chair and spokesperson for the 2007 event.

"Support from people and organizations across Canada is essential to the success of the Walk," says Werner. "I want to thank all WALK for ALS participants, volunteers, pledges and sponsors for their commitment to making the 2006 WALK for ALS so successful. Your dedication and enthusiasm has been inspiring."

The ALS Society of Canada is thrilled to have Werner back in the role of national chair and spokesperson for the 2007 event.

2006 Top five WALK for ALS fundraisers:

1. Sidney Valo, ON $29,035
2. Gary Aikema, ON $21,660
3. Lara Gee, ON $19,666
4. Terry Layden, AB $16,890
5. Gary Spence, NS $16,682
Over the past few months much progress has been made in securing grants and funding for ALS research. With a number of successful fundraising ventures completed, including the Elizabeth’s Concert of Hope (ECOH) nationwide tour and the great success of the 2006 WALK for ALS, this upcoming year promises many more developments for the ALS Society of Canada.

Research

The Neuromuscular Research Partnership (NRP) peer review for relevancy was conducted last June. Eighteen submissions were made for NRP grants with a total of nine grants granted, two of which were fully funded by Canadian Institutes of Health Research and seven funded through the NRP.

On September 5, 2006, the ALS Society of Canada welcomed Dr. Denise Figlewicz as our first director of research. Dr. Figlewicz has been involved in the ALS research field since the 1980s. This is a newly created position for ALS Canada. Dr. Figlewicz will lead the development and implementation of a national ALS research strategy, represent ALS Canada among scientific communities, and act as an advisor to government and industry.

On September 22-23 David Cameron participated in the first ALS Society of Manitoba ALS Conference, held in Winnipeg, which was an outstanding success. The theme of the conference was "ALS/ Lou Gehrig’s Disease: Exposed". Two of the speakers were Dr. Michael Strong, medical director at the ALS clinic in London, Ontario who presented on “Recent Advances in the Management of ALS,” and Dr. Wendy Johnston, medical director at the ALS clinic in Edmonton, Alberta who presented on “Spirituality and ALS” and “Palliative care in ALS”. More than 80 delegates attended the conference including a significant number of physicians.

On September 30th the Hike 4 ALS took place at the Kortright Centre north of Toronto and a number of other locations across the country. At the Toronto site, there were more than 100 hikers, a significant growth over the previous year. The hike helped raise more than $42,000 for ALS research and support for those living with ALS.

Last fall, we held a peer review process for selection of this year's Doctoral Research Awards where two young researchers were granted three-year support grants. We also held a meeting to conduct a peer review for relevance for the first competition for the Tim E. Noël Fellowship in ALS Research. Again, we have partnered with the CIHR and used their processes to select three Tim Noël recipients with ALS Canada fully funding one, and ALS Canada and CIHR co-funding the other two.

With respect to our relationship with other organizations, the President & CEO is a member of the board of directors of the International Alliance of ALS/MND Associations, and presented a white paper on patients’ rights at the meeting in December. At the same meeting, he also presented to the Alliance members and the participants in the International Research Symposium the special attributes of Toronto for 2007 when the event will be hosted by ALS Canada from November 27 - December 3.

The ALS Society of Canada hosted its 3rd annual Research Forum March 23 - 25 in Toronto. This forum brings together members of the Canadian research community to address important questions about underlying biology of ALS development and implementation of effective therapies to improve quality of care, and how ALS Society of Canada can best facilitate these efforts. More than 90 researchers and young investigators participated in the forum.

We are proud to announce that for the first time in the history of the ALS Society of Canada, we have surpassed the $1 million mark in contributions for research funding. This milestone reflects the hard work put in by the ALS Society and our many supporters.

Together with your help and support we are continuing to make a difference in the lives of people living with ALS and their loved ones. Our efforts on both local and national levels, whether it be through fundraising, volunteering, research, and donations are invaluable to helping the ALS Society of Canada achieve its ultimate goal of finding a cure for ALS.
WALK FOR ALS

The WALK for ALS is a Canada-wide annual fundraising event held in partnership with the ALS Society of Canada and the provincial ALS Societies. The purpose of the Walk is to raise funds for provincial services to people living with ALS and their families, to fund much needed research for an effective treatment and ultimately a cure for ALS, and to spread awareness about this devastating disease.

The number of Walk participants has increased steadily since the first Walk in 2001. Last year there were approximately 10,500 participants who generated more than 105,000 individual pledges.

"Planning the WALK for ALS is a collaborative process," says Gillespie. "With such high numbers of participants involved with close to 80 local walks Canada-wide, the challenge for ALS Canada is to be sensitive to the varying needs of the organizing volunteers and the walkers. Our goal is to provide the best support possible to all of the provinces in their marketing and fundraising efforts."

This year, national gold sponsors are Canon Canada and Hbc; the national bronze sponsor is Philips, Hager & North Investment Management Ltd.

Prizes and incentives are provided to top fundraisers through national and local sponsors. ALS Canada provides the $100 raised incentive item for all eligible participants. A Canon digital camera (courtesy of Canon Canada) is awarded to the top fundraiser in each province. A historic Hbc blanket throw (courtesy of Hbc) is awarded to the top fundraiser in each Walk location across Canada. Our Walk web site provides information on prizes and incentive items at http://www.als.ca/WALKforals/.

Participants can register online via the web site. Donations can be made online by credit card. Participants who register online have an opportunity to create their own web page with a personal user profile, photo and information, as well as access to online fundraising tools. Through online fundraising, participants can receive donations from friends and family anywhere in the world.

The ALS Society of Canada is always looking for individuals and volunteers willing to make a difference in the lives of those living with ALS. Other than the WALK for ALS, supporters are encouraged to hold their own events to help raise awareness and funds for ALS in their respective communities.

For more information please visit: http://www.als.ca/fundraisingevents/ and http://www.als.ca/events/event.aspx?id=7
MONCTON WALK FOR ALS

Carrie Smith

2007 marks Smith’s second year as walk co-ordinator. In 2006, her team managed to more than double the funds raised to $47,000 up from $22,000 the previous year.

Despite having no prior experience in fundraising, Smith managed to secure a local newspaper interview with her brother Mike, and the two of them appeared on Global News and CBC news to help raise awareness about ALS and the Moncton Walk.

“This year I looked deeper, I figured out what we need and how to get people excited and put it into play,” says Smith. “I raised the stakes on the incentives. Seeing that most of my fundraisers were in the less than $100 category, I wanted to push them to $100.”

Some of this year’s incentives over the $100 bracket include three months at a local weight loss clinic, three months of free house cleaning, a ballot for a trip to a sunny travel destination, or a key that gives eligible participants a chance to drive away with a car on a two-year lease. The contest for the car will take place on the day of the Walk.

“I asked a local dealership to help me raise excitement for our fundraising. With the possibility to win a new car, we will be able to raise a lot more money by pushing our fundraisers into the next bracket. We will help more families that way. If we push each person just a few dollars further, it will add up on its own,” says Smith.

All participants who raise less than $100 will receive a free one month membership at a local fitness club.

As far as media coverage of the event, Smith has secured two television interviews and three radio station interviews with her brother Mike, as well as an article to appear in her local paper. She has also secured an interview with Walk spokesperson Zack Werner and has ensured that media coverage will be present at the Walk.

HOLDING OR HOSTING AN EVENT? KNOW SOMEONE OR A COMPANY WHO IS? PLEASE CONSIDER A FUNDRAISER IN SUPPORT OF ALS

You can provide Hope through research and Help to people living with ALS (Lou Gehrig’s Disease) through a fundraising event supporting the ALS Society of Canada. Golf tournaments, garage sales, family or company celebrations are just a few ideas for holding a fundraising event in support of ALS research and care.

ALS is a devastating disease and needs more attention. People with ALS can only hope that one day a cure or treatment will be discovered for them and for the tens of thousands of Canadians alive and healthy today that will die from ALS.

For more information on how you can help please visit www.als.ca or please call: 1-800-267-4ALS ext. 228

ALS. Three letters that change people’s lives. FOREVER.
RAISING HOPE FOR ALS IS A FAMILY AFFAIR

When Carrie Smith's brother Mike Smith was diagnosed with ALS in 2005, at the age of 33, she was devastated. Not only is he her brother, but he is also her best friend.

Father of two-year-old twins and former member of the Canadian military, Mike had recently returned from an overseas mission when he received the news that he had ALS.

"A person learns very quickly the value of life and what is important when they themselves and their family are faced with a terminal illness. One day you have all the time in the world, starting a family, experiencing the gift of life, finally getting the transfer back home, and then some force puts a three to five year time limit on it," says Smith.

When Smith learned that her brother had ALS, she immediately decided to do anything in her power to help him and his family. That's why she decided to organize the Mike Smith Fund WALK for ALS in Moncton, New Brunswick last June.

"My brother and his family held in his diagnosis for a year without telling us. Their selflessness and courage is to be admired. Could you imagine not watching your children grow? So many things are being robbed from my brother: Not possessions, but life and its experiences. Not university applications for his children, but teaching them to talk, read, play ball, or ride a bike. I kept asking myself, why Mike? What did he ever do? Why not me? I felt anger and denial, helplessness and fear," says Smith.

After going through every possible stage of grieving and scouring the internet for "the cure that someone must have overlooked," Smith came across the web site for the ALS Society of New Brunswick.

Smith decided to join the Society's fundraising committee, but at her very first meeting, former Moncton WALK for ALS co-ordinator Shirley Smallwood, announced she would be stepping down from her position.

"I knew right then what I had to do, and I did," says Smith, who decided on the spot to take over the position of walk co-ordinator.

As well as the WALK for ALS she has also organized additional fundraising events including a spin-a-thon collaboration with her local YMCA and a draw for a Harley Davidson motorcycle.

Although Smith's brother Mike has ALS, the family remains optimistic for the future. "Mike was diagnosed with ALS four days after his wife Lisa gave birth to twins. They had tried for eight years to become pregnant, and with twin boys and a girl, it was a miracle," she says. "Now we focus our energy on letting Mike know that we are trying our hardest to fund a cure. It is out there, and we just need a little time." Smith, who has three children of her own, prays every day that Mike will have a chance to watch his kids grow up.

With her busy schedule as walk co-ordinator and raising three children, Smith still finds time to help other walk co-ordinators as much as she can. "This has become so much more for me than I had ever expected," says Smith. "My legs will carry my big brother Mike and me for the rest of my life across the finish line to help other people living with ALS. I am visiting families and I am loving and caring more than I ever thought I could. Mike and I may not find the cure, but we sure have found hope."

GLOBE REPORT HELPS SPREAD THE WORD ABOUT ALS

A special supplement about ALS is to appear in The Globe and Mail on April 26, 2007. The main goal of the report is to help increase public awareness about ALS. This is the first time that the ALS Society of Canada has published a report in a national newspaper, and the Society hopes it will be an important tool in generating public support towards this devastating disease.

"We are pleased to announce a partnership with The Globe and Mail newspaper that will see the publication of a special national report on matters important to friends and supporters of the ALS Society of Canada", says president & CEO David S. Cameron.

The report will include information about ALS, and will touch upon a wide range of topics relating to the disease.

The Globe and Mail reaches more than 1.3 million readers nationwide, every day. In addition to the print version, the supplement will also be available online at globeandmail.com.
As a child, it is often difficult to cope with the life-altering experience when a parent is diagnosed with ALS. Between the pain and devastation of watching a parent succumb to the disease, and watching the other parent (or adult) in the household take on the demanding and time-consuming role of caregiver, it is often difficult for a child to come to terms with their own feelings of guilt, abandonment, sorrow and confusion.

The ALS Society of Canada has launched a new program to help children during this difficult period in their lives. Through als411, Jane McCarthy director of services & education at ALS Canada is helping children find a place where they can learn more about ALS, and how it affects them.

With their friends not being able to fully understand the impact of ALS on the family, and the adults in the household being preoccupied in the role of caregiver, children are often forced to make drastic lifestyle changes, and many feel that they are alone. Children often choose not to tell their friends about what's going on at home for fear of being forced to explain. Often children whose parents have ALS may themselves be unsure of the facts, or may find the disease much too painful to talk about with friends who just "don't understand" what they're going through.

als411 - Everything you need to know
A few years ago, McCarthy conducted a needs and opportunities assessment - Enhancing Services and Education Project. One of the unmet needs identified was support for children. Because of the fairly low prevalence of ALS, children whose parents have ALS are less likely to know peers who are in the same situation.

In December 2006, McCarthy launched als411. The web site, at http://www.als.ca/allforkids/, is available in French and English, and provides children with easy-to-read resources about the disease, links to other sources of information, and suggestions for ways to help them cope. McCarthy chose to name the program als411 because 411 has become the colloquial shorthand for "everything you need to know," especially among young people.

Through the web site, McCarthy has managed to present facts about ALS in a way that's easy for kids to understand. The web site features a wide range of resources dealing with issues from how to cope with feelings and emotions when a parent is diagnosed with ALS, to true stories and testimonials from other children who survived the loss of a parent to this devastating disease. The web site also features a section for parents, providing suggestions on how to talk to their children about ALS. Through the web site, McCarthy hopes to provide a multi-faceted resource to help with outreach.

The site also includes a list of all the provincial ALS societies so that parents can contact them to learn what support may be available in their province.

To obtain the testimonials, McCarthy conducted several interviews with Canadian youth who have lost a parent to ALS in order to create a comprehensive resource for other children whose parent has ALS. The booklet is available on the web site and will be in print later this spring. McCarthy hopes this resource will help by sharing the experience and
ALS411
Continued from page 6

wisdom of others with kids who are living the ALS journey now.

Provincial resources
In addition to als411, some provincial ALS units in Canada also have resources for children. The ALS Society of New Brunswick has the Support for Champions program, later adopted by the ALS Society of Alberta. Through the Support for Champions program, children who have a parent with ALS are eligible to receive funding through the society. The funding is aimed at helping these children lead typical lives through participation in childhood activities. Swimming, piano, soccer and other after-school activities all cost money. The program helps pay for some of those activities.

"The children are often the forgotten ones in the ALS journey, not by design but rather because of the overwhelming circumstances," says Gilles Leblanc, former president of the ALS Society of New Brunswick. "It shouldn't be that way."

ALS Alberta also supports its own unique program to help youth get involved in the ALS community. Youth AntiLateS ALS offers ideas for fun ways that youth can get involved in supporting the ALS Society in their own way.

"We talk about ALS as a family disease," says McCarthy. "But until now, we've focused on the spousal support and equipment issues. It's important to recognize the role children are playing as caregivers and how their lives are changing as well."

Future plans for the web site include a feature on young people doing amazing things such as caregiving, raising awareness about ALS, and various fundraising ventures. McCarthy hopes to give children a forum to talk about their stories and achievements. She encourages kids to send in their stories and video clips. McCarthy also hopes to include more costly features down the road such as interactive, animated games and puzzles, provided that funds can be secured. Volunteers and/or donations for als411 are always welcome.

Feedback on als411 is appreciated and can be done by e-mailing: als411@als.ca.

THE CHARITY GOLF CLASSIC - IN MEMORY OF TIM E. NOËL

On June 26 the ALS Society of Canada will again host its annual Charity Golf Classic - in memory of Tim E. Noël. The golf tournament will be held at the Sleepy Hollow Golf Course in Stouffville. All proceeds from the tournament go to the ALS Society of Canada - in memory of Tim E. Noël.

TIM E. NOËL "Don't feel sorry for me. Help me help others."

Tim Noël lived by these words during his two-year fight with ALS. And, for those that knew him, that comes as no surprise. His optimistic outlook toward life remained strong and helped lift the spirits of everyone around him. Despite his diagnosis in 1999, Noel continued his work as deputy governor for the Bank of Canada until his death in 2001. He worked for the Bank of Canada for 34 years - six of those as deputy governor.

As a distinguished central banker, Noël was held in high esteem within the investment community. News of his diagnosis mobilized several friends to build the Tim E. Noël Endowment Fund, through the Tim E. Noël Golf tournament to help fund ALS research. That fund grew to $1.3 million and last year the Tim E. Noël fellowship in ALS Research was created.

Noël was very articulate about the needs of people with ALS. He gave of himself at a time when every day held special challenges. He left us with one of his favorite sayings, told to him by a good friend.

"Today is a gift. That's why they call it the present. And, you should never let the thieves of yesterday or tomorrow rob you of that gift."

To join us as a golfer, sponsor, or dinner guest please contact: Enzo Raponi, 416-497-2267, ext. 205, er@als.ca
UNITED IN SONG: ELIZABETH’S CONCERT OF HOPE SPREADS HOPE ACROSS THE NATION

Since 2001 Elizabeth Grandbois has been changing the lives of those living with ALS and their caregivers for the better by hosting the annual Elizabeth’s Concert of Hope event in her town of Hamilton, Ontario. This year, Elizabeth’s Concert of Hope went on the road across Canada, raising awareness about ALS.

To date, the concerts have raised more than $2-million for ALS research and mobility equipment.

2006 marked the 6th year of Elizabeth’s Concert of Hope, culminating in a nationwide concert tour from Vancouver to Corner Brook. The seven concert tour, co-directed by Kevin Hicks of Theatre Cares and sponsored by Tim Hortons, Via Rail and BBDO Toronto, also made stops in Calgary, Winnipeg, Regina, Halifax, and Summerside. Each concert featured its unique Canadian music lineup, focusing on the individuality and personality of the respective community.

In Vancouver, the concert was held at the North Vancouver Centennial Theatre. Top Canadian artists such as Tom Cochrane and Barney Bentall brought the tour to a fantastic start.

In Calgary, the event was held at the Jack Singer Concert Hall. The show kicked off with a white-hat ceremony, a symbol of Calgarian hospitality, with the musical stylings of Murray McLauchlan, Tara McLean, Kim Stockwood, and Marc Jordan.

In Winnipeg the concert took place at the Pantages Playhouse Theatre. The city proved a committed and warm participant in Elizabeth’s Concert of Hope, hosting a culture-rich concert featuring Ian Thomas, Suzan Aglukark and Vasil Popadiuk.

In Regina, the show took place at the Conexus Arts Centre. The concert team noted a remarkable outpouring of support from individual Rotarians among the crowd. Performances by Cindy Church, Brad Johner, and Jeff Healey’s Jazz Wizards added a final touch to the night’s magical vibe.

Healey’s Jazz Wizards added a final touch to the night’s magical vibe. The contribution of Halifax’s small businesses proved vital in their support, and the intimate event featured prominent Canadian acts Glass Tiger and Jacksoul. The event took place at the Seahorse Tavern, a venue perfectly suited to the laid back feel of the evening.

The devotions of the Summerside community was unparalleled, as they honored their key sponsor, David W. Rodd, at the Harborfront Jubilee Waterfront Theatre. Accomplished scholar and businessman, Rodd was the owner and founder of Rodd Hotels and Resorts, a leader in the hospitality industry across Atlantic Canada. He passed away four weeks after Elizabeth’s Concert of Hope came through his town.

In Corner Brook, tickets to Elizabeth’s Concert of Hope sold out three weeks prior to the event, an enthusiasm that could be clearly felt throughout the Corner Brook Arts and Culture Centre on the night of the performance. “This will mean great strides for the Newfoundland ALS Society,” states Cheryl Power, executive director of ALS Newfoundland & Labrador, who lost her father to the disease. “We need money for our patient services, we definitely need more equipment... with the amount of people we have with ALS on the island, it's a great endeavor to meet their needs.”

Corner Brook was the last stop on the Elizabeth’s Concert of Hope tour, bringing a triumphant close to the spirit of joy and celebration felt across the country.

The 2006 concert tour raised more than $550,000 for ALS. Not an easy feat for any individual, let alone someone who’s spent almost a decade living with the overwhelming and devastating effects of ALS. Grandbois is taking some time to rest and re-energize after her successful run as visionary and director of Elizabeth’s Concert of Hope, but is currently working on future plans including a second concert in

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DENISE A. FIGLEWICZ, PhD
DIRECTOR OF RESEARCH

Denise Figlewicz, PhD, joined the ALS Society of Canada on September 5, 2006. Figlewicz's research career has focused on mammalian nervous system development and pathology, specifically molecular genetic and cell approaches to investigate neuromuscular diseases such as ALS. She has been involved in the ALS research field since the 1980s.

Figlewicz received her PhD in biochemistry and completed her post-doctoral work at the National Institutes of Health and National Naval Medical Research Institute, both in Bethesda, Maryland.

Prior to joining ALS Canada, Figlewicz was associate professor and research scientist, neurology department, University of Michigan, Ann Arbor, Michigan.

In 2004, she began a new initiative to identify ALS susceptibility genes, taking advantage of the genetic differences between different inbred mouse strains to study alterations of the motor neuron diseases phenotype in mutant SOD1 over-expressing mice.

Her research has taken advantage of the powerful new methodologies of molecular genetics to better understand the pathogenesis of human neuromuscular disorders, both inherited and sporadic.

In 1993, Dr. Figlewicz and Dr. Guy Rouleau were part of the international consortium that discovered the first gene responsible for the familial form of ALS. This breakthrough paves the way toward the development of treatments for the hereditary form of the disease.

She has authored more than 75 articles in peer-reviewed publications such as Journal of Neurochemistry, Journal of Neuroscience, Neurology, Muscle & Nerve, Nature, Annals of Neurology, and Nature Genetics.

Her scientific activities include being a reviewer for Muscular Dystrophy (U.S.), Muscular Dystrophy Canada, Medical Research Council of Canada, Motor Neurone Disease Association, U.K., French Muscular Dystrophy Association, National Institutes of Health (U.S.), The ALS Association, the Welcome Trust, U.K., as well as a reviewer for numerous scientific journals.

At the ALS Society of Canada Dr. Figlewicz will lead the development and implementation of a national ALS research strategy focusing on understanding the cause and cure for ALS. She will represent the Society among scientific and research communities world-wide and will act as an advisor to scientists, government officials and industry leaders seeking advice in the ALS research field.

United in song: Elizabeth’s Concert of Hope spreads hope across the nation

Vancouver (to be held November 16, 2007).

"Involving individuals from the ALS community in organizing, publicizing, and implementing such an event will empower all involved and give them a true sense of ownership of the project" Grandbois states. "I want others to be empowered to take greater and bolder steps to increase the focus on those living with ALS, to carry on the momentum of building awareness."

Grandbois still plans to continue public speaking and raising awareness about ALS "until I can no longer do it." As for Elizabeth’s Concert of Hope, Grandbois says: "the foundation would be pleased to facilitate and assist those wanting to host a Concert of Hope event. I am working on future plans, please stay tuned."

Her message of hope and compassion can be felt in her words, her actions and her many selfless contributions to the ALS community. Always optimistic, determined, and enthusiastic in face of adversity, Grandbois remains positive for the future of others living with ALS.

It is a wonderful life, it's a wonderful world and there are so many good people in it. We need to hold onto our dreams and continue to build new ones. My dreams - there have been a lot of them, and nightmares too - have all helped set me free."

- Elizabeth Grandbois
INTERVIEW WITH DR. DENISE FIGLEWICZ

Dr. Denise Figlewicz sees her transition from bench research to administration as a natural direction for her career, not just a change in focus. "As one moves from a junior to a senior investigator, time at the bench diminishes and time spent in front of the computer, giving talks, teaching, writing, reviewing grants, and travelling to conferences increases," she says.

After years of being a hands-on researcher, Figlewicz has established many contacts, and these form the basis of experimental collaboration and exchange of ideas. "There is a limit to what you can do at the bench in your own laboratory. There's no limit to the ideas you come up with either alone or together with other colleagues," she adds.

Figlewicz sees finding effective ways to fund clinical research as a challenge. "The actual funding may not come from the ALS Society, but from drug companies and federally funded programs. I need to identify a role for the ALS Society in facilitating this process," she says.

Having a highly respected scientist such as Figlewicz at ALS Canada will contribute to raising the profile of ALS research. "It is critical to support the great group of Canadian investigators already well-established and productive by identifying the specific needs for which additional investment of funding will make a large difference. A second approach will be to facilitate collaborative efforts among Canadian investigators, and with other scientists and clinicians worldwide," she says.

Figlewicz also hopes to encourage talented researchers to enter the field of ALS research by providing support and opportunities for involvement to young investigators. Her immediate goal for established Canadian investigators is to acquaint herself with their work in neuroscience/neurodegeneration, and also in research technology development. "There is considerable talk these days about stem cells and stem cell research. Yet, there are other areas of research in biomaterials and bioengineering where technology might be harnessed to improve ALS diagnostics, drug/therapy delivery, palliative care and overall quality of life," explains Figlewicz.

Funding is also a big part of the research equation. Research requires laboratory space, modern equipment and supplies, and well-trained personnel. The investigator also needs to stay current by attending conferences and learning new methodologies. "None of these are possible without funding. I am not talking about just quick fixes, but a true investment in the development of research programs for individual investigators and for groups of collaborative researchers," says Figlewicz.

"I also think there are additional opportunities for funding partnerships such as those already in place (Neuromuscular Research Partnership and The ALS Association in the U.S.)," she adds.

Research in Canada reflects a number of current ALS themes worldwide. According to Figlewicz, themes include motor neuron biology, cytoskeleton*, and handling of mutant or misfolded proteins; genetics including the identification of genes and their role in disease development; neuroprotection* provided by trophic factor* support of motor neurons; the role of inflammation and the contribution of cells surrounding motor neurons; intracellular pathways related to neuronal death; role of exogenous toxins*; excitotoxicity*; development and use of model systems to test putative therapeutics*; and delineation of clinical phenotypes, including involvement of additional regions of the nervous system.

Figlewicz represented ALS Canada at the 2006 International ALS/MND Conference in Japan. She gave a presentation on the SOD1 mouse as a model of sporadic ALS, the research project she has been working on since 2004. Her research demonstrates that mice now being used for research can be manipulated to create more diverse models of how ALS occurs and progresses in humans.

* Scientific terms:
cytoskeleton: the interior structure that maintains a cell's structure
neuroprotection: strategies to protect neurons from injury or degeneration
trophic factor: a natural cell growth and survival molecule
exogenous toxin: toxins originating outside of the body
excitotoxicity: over stimulation of nerve cells by nerve impulses, often leading to cell damage or death
putative therapeutics: drugs that are believed to be effective treatments, but haven't yet been proven
clinical phenotype: observable physical or biochemical characteristics of an individual subject/model
ALS Canada is co-funding three Canadian ALS researchers with The ALS Association (U.S.). Christopher Shaw will receive a three-year grant at $80,000 per year. Sanjay Kalra and Minh Dang will receive $40,000 each for one year and will be eligible for traditional three-year grants on completion of their initial grant.

Christopher Shaw, PhD, associate professor of ophthamology and associate member within the departments of physiology and experimental medicine at the University of British Columbia, is investigating a connection between chemicals used in food processing and vaccines and ALS.

Shaw and his team are studying ALS and ALS-parkinsonism dementia complex, an unusual neurological disease of Guam. Researchers believe that this disease is caused by a neurotoxin in the seed of the cycad, a staple in the Guamanian diet. Grant funding for this project will help determine if sterol glucosides (a neurotoxin) or their metabolized forms are present in higher levels in the blood of people living with ALS. The presence of these compounds will serve as important biomarkers (biochemical features or facets that can be used to measure the progress of disease or the effects of treatment) to make earlier diagnosis of ALS possible.

Shaw has successfully isolated several neurotoxins and examined their mechanisms of action leading to neural cell death. His team has also devised a battery of behavioral tests to measure motor and cognitive function, and the sense of smell against changes in cellular structure and biochemistry. In this study, Shaw will use medical resonance imaging to examine cellular changes in control and cycad fed mice. He hopes this research will lead to therapeutics to prevent the initiation and progression of neural death in ALS.

Dr. Sanjay Kalra, is an MD, assistant professor, division of neurology and co-director of the ALS clinic at the University of Alberta. One focus of Kalra’s research has been studying neurochemical and structural changes in the brain of people living with ALS using various neuroimaging techniques.

A variable degree of cognitive impairment is present in up to 50 per cent of people living with ALS due to brain degeneration outside of areas that control movement. Kalra’s study aims to determine the extent to which brain chemical abnormalities exist in ALS and if they contribute to the development of cognitive impairment.

The neurotransmitters glutamate and gamma-aminobutyric acid (GABA) will be measured in regions of the brain that control movement and cognition in people living with ALS using high-field magnetic resonance spectroscopy (MRS). Glutamate and GABA respectively cause excitation and inhibition in the brain. Abnormal levels of either compound can alter the balance between excitation and inhibition and may be responsible for the development or progression of the disease.

A better understanding of the biochemical alteration associated with cognitive impairment may explain why some people with ALS suffer from cognitive impairment while others do not and would provide a more rational framework for designing treatment strategies. Brain glutamate and GABA may also serve as objective tests to make earlier diagnosis possible and monitor the progress of therapies for ALS.

Nguyen Minh Dang, PhD, assistant professor, departments of clinical neurosciences, cell biology & anatomy, biochemistry and molecular biology, faculty of medicine at University of Calgary, wants to understand neurodevelopmental and neurodegenerative disorders caused by the disruption of the cellular structure and altered cell signaling.

During his post-doctoral training in the laboratory of Dr. Li-Huei Tsai at Harvard Medical School, Minh Dang co-discovered, Ndel1, a new protein that helps keep neurons intact. Ndel1 is an important regulator of the cytoskeleton (a dynamic structure that maintains cell shape and enables some cell motion) and supports growth and maintenance for neurofilaments (long fibers of neurons).

With this funding, Minh Dang’s group will seek a role for the Ndel1 protein in the health of motor neurons. If the research discovers that Ndel1 is implicated in ALS, this protein could prove a useful target for ALS therapeutics.

In addition, strategies preventing cytoskeletal collapse and boosting the regenerative program of injured axons (long slender fibres of nerve cells) will be developed for combating ALS. By understanding the dynamics of the cytoskeleton, scientists might be able to slow down motor neuron degeneration, stop loss of axons and favor their regeneration.
INCREASING THE PROFILE OF ALS RESEARCH

Last fall, the first-ever Tim E. Noël Fellowships in ALS Research were awarded to Edor Kabashi, Joe V. Chakkalakal and François Gros-Louis.

"The awards are a wonderful example of leveraging of funds and increasing the profile of ALS research in the young scientific community," says president & CEO David S. Cameron, at the ALS Society of Canada.

Each candidate is eligible to receive the fellowship valued at up to $55,000 annually for up to three years, using funds from the Tim Noël endowment fund. The fellowship was awarded through the CIHR fellowship competition, using its peer review process for the determination of scientific merit of the applications for funding.

Edor Kabashi is a post-doctoral PhD fellow working with Dr. Guy Rouleau at the neurogenics laboratory at the Centre Hospitalier at Université de Montréal. His project is entitled "Developing and characterizing novel models of ALS and other neurological disorders in zebrafish." In 2006, he completed his PhD in neurology and neurosurgery at McGill University.

Approximately 10 per cent of people with ALS have the inherited form of the disease. Animal models, in particular mice, have been developed to study mutant superoxide dismutase (SOD1) induced toxicity responsible for motor neuron damage in those living with ALS. However, more than a decade of extensive studies on mice has failed to find a successful treatment because transgenic (gene-mutated) mice are not suitable for high-intensity drug discovery. Zebrafish expressing the mutant SOD1 gene have recently shown greater promise than mice as a model to study inherited ALS. Zebrafish are easier to breed, have shorter disease generating times and are more cost effective. Transgenic zebrafish will allow for screening of high-intensity drug treatments. The most successful can then be tested on mutant SOD1 mice and eventually on those living with ALS. Kabashi is hopeful this new model will explain the selective degeneration of motor neurons and lead to the development of therapies to help those who suffer from this devastating disease.

Kabashi was one of ALS Canada's first recipients of the Doctoral Research Awards given in 2005 for his project, "Problems with protein disposal in ALS," to illustrate misfolded protein in ALS pathogenesis using transgenic mouse models.

Joe V. Chakkalakal's project is entitled "The establishment of motor unit homogeneity during development and after axon regeneration." He is a PhD candidate at the University of Ottawa in the department of cellular and molecular medicine and will be a post-doctoral fellow in the laboratory of Dr. Joshua Sanes at Harvard University in Cambridge, Massachusetts.

Recent studies of animals revealed variations in how different motor neurons respond to degeneration. Of particular relevance is that certain types of motor neurons display compensatory behavior while others are more susceptible to injury. Although it's not known why some motor neurons are more susceptible to injury, it's known that motor neurons differ according to the types of muscle fibers they innervate.

Chakkalakal wants to use the most up-to-date imaging technology available to study how motor neurons and target muscle fibres communicate during normal development and after injury in transgenic ALS mouse models. Screening of SOD1 mice could find the factors that promote compensatory behavior. Chakkalakal hopes his research will contribute to the discovery of therapies to stem the relentless progression of ALS.

François Gros-Louis' project is "Identification of misfolded proteins associated with sporadic ALS through innovative proteomics approaches." He is a post-doctoral fellow in Dr. Jean-Pierre Julien's laboratory affiliated with the department of anatomy and physiology at Laval University in Quebec City. Gros-Louis completed his PhD at the department of human genetics at McGill University in 2006.

Most studies on ALS have focused on identifying the genetic mutations of inherited ALS and examining the toxicity of mutations in the SOD1 gene responsible for only two per cent of ALS cases. The majority of people living with ALS have the sporadic form of the disease.

Gros-Louis wants to be the first to identify abnormally-shaped proteins associated with sporadic ALS using a proteomics-based approach that involves the identification of proteins in the body and their role in physiological and pathological functions. This project will lead to new diagnostic tests for early detection of the disease, the development of new therapeutic targets and, hopefully, new drugs to cure ALS.

By funding the research of these candidates, the ALS Society of Canada hopes to come closer to achieving its vision of finding a cure for ALS.

About Tim E. Noël

Tim E. Noël was the deputy governor of the Bank of Canada and died of ALS in July, 2001. He continued to work full-time, showing up each day with his ventilator and wheelchair. The funds from the endowment fund come from the Tim Noël endowment fund. The Tim Noël endowment fund come from the Tim Noël golf tournaments organized by Noël's friends who were inspired by his courage and battle with ALS.
LAB TESTS SHOW VACCINE MAY DELAY MORTALITY IN FAMILIAL ALS

A new study led by ALS researcher Jean-Pierre Julien PhD of Quebec's Laval University suggests that a new vaccination, using mutant SOD1 was successful in delaying motor neuron damage in mice immunized before the disease's usual onset. The study was published in the February 13 issue of The Proceedings of the National Academy of Sciences.

The mice, who lived on average a month longer than those who were not immunized, also showed significantly less motor neuron death overall.

"The encouraging results we've seen make us eager to refine this immune-based approach to see if it will ultimately help people with familial ALS," says Julien.

In familial ALS, the mutant gene SOD1 produces a toxic protein that contributes to the death of the nerves that control muscle movement and leads to the development of ALS.

However, those who have normal SOD1, do not develop the disease.

"In this paper, we report that vaccination with mutant SOD1 was effective in alleviating disease symptoms and delaying mortality in two ALS mouse models. From these results, we propose that immunization against SOD1, and especially passive immunization approaches, should be explored as a potential therapeutic approach for human ALS cases linked to SOD1 mutations," says Julien.

PADDLING ACROSS NORTHEASTERN ONTARIO FOR ALS

Two women paddled their canoe and portaged through the rocky Canadian Shield for seven weeks to raise awareness and funds for ALS research.

Thousands of bikes pass through the Shield weekly on cross-Canada rides. Anne-Marie Fortner and Hélène Marcoux decided to do something different by paddling 1,000 km from Winnipeg, Manitoba to Thunder Bay, Ontario. They set out from the forks of the Red River in Winnipeg on July 12 and reached Thunder Bay on Lake Superior on August 31.

The women were at the mercy of the elements and constantly going upstream. "The biggest challenges for us are the wind, the heat, finding good water and turning out aches and pains," Marcoux says.

Fortner said she paddled for her mother, Franca, who was diagnosed with ALS two years ago. "My mother's diagnosis is just incentive to raise awareness for the cause and raise some money for research, because there is no cure," says Fortner. "She's really proud of me and really thankful."

Marcoux and Fortner raised approximately $6,000 over their seven-week journey and counted on the goodwill of people they met to take them in. All donations were directed towards the annual WALK for ALS in London, Ontario.

BETTY'S RUN FOR ALS

Sunday, June 10, 2007 marks the date of Betty's Run for ALS in Calgary, Alberta. Betty Norman was an active Calgarian who was diagnosed with ALS at age 58. Realizing the lack of ALS awareness and research funding, she began Betty's Run for ALS in 1996. Betty lost her battle with ALS in 1997, only two weeks after the first Betty's Run for ALS, but her spirit and vision still live on through the run each year.

After a decade of fundraising efforts, Betty's Run for ALS has raised more than $2.4 million for ALS awareness, patient services, equipment, and research. Last year's 10th anniversary run raised $426,547, the highest grossing fundraising event for ALS Alberta in all of 2006. More than 1,300 people participated in the event.

"Betty's Run for ALS is not just about raising much-needed funds for finding a cure, and for providing services to ALS patients. It is about raising awareness, raising spirits, and ensuring that hope remains the constant theme in all our lives," says 2006 ambassador Dwain Pitre.

For more information please visit the ALS Alberta web site at www.alsab.ca or call 403-297-0569.
A newly discovered protein could be the key to designing new therapies to help with disease management in ALS and some cases of frontotemporal dementia (FTD), a type of dementia associated with ALS.

A multi-centre team of neurologists led by Dr. Virginia Lee, director of the Center for Neurodegenerative Disease Research at the University of Pennsylvania found that a buildup of the same malformed protein is responsible for nerve cell damage in both neurological disorders.

The misfolded protein, known as TDP-43, was identified in regions of the nervous system specific to ALS and FTD.

"It suggests that maybe if a treatment can be found that works for ALS, it might work for FTD too," says Dr. Bruce Miller, a neurologist on the multi-centre team responsible for the breakthrough.

TDP-43 is found in cells throughout the body and is suggested to somehow regulate splicing, an intermediary step in the synthesis of proteins. Thus, TDP-43 is normally found in the cell nucleus. However, the protein, or fragments of it, were also identified in the cell body and processes of affected neurons. Scientists are still unsure as to why certain populations of cells are more susceptible to the disease protein than others.

The deformed proteins are detected in the neuronal cell bodies and then "tagged" by another substance known as ubiquitin; ubiquitinated proteins are transported to the proteasome, which serves as an intracellular waste processing machine. However, in the case of the diseased neurons, the ubiquitinated proteins instead aggregate to form what scientists refer to as "inclusions".

Instead of undergoing the normal breakdown processes, the inclusions build up in specific neurons in the brain and spinal cord, becoming progressively more widespread. The buildup results in toxic consequences for the central nervous system.

Although the damaged protein has been isolated, researchers are still searching for a way to change the protein's form or methods to reverse the toxic buildup it causes in the nervous system.

Researchers are optimistic as to the new breakthrough, and are confident that the discovery will be integral at paving the way for further research into the disease process.

"This study is exciting for several reasons," says Denise Figlewicz, director of research, ALS Society of Canada. "It provides some very solid evidence in favor of the hypothesis that there is a spectrum of diseases ranging from predominantly FTD to predominantly motor neuron degeneration/ALS, and including co-occurrence of the two neurodegenerative syndromes in the same individual. It also identifies a specific target of aberrant intraneuronal function and thus, part of the molecular neurodegenerative pathway(s) which are in common in ALS and FTD. Finally, it opens the door to very focused research approaches to identify what pathway(s) are involved upstream and downstream of TDP-43 ubiquitination and how they may be manipulated to halt or diminish the buildup of the inclusions."

The findings were published on October 6, 2006 in the journal Science.

Swim for Life - Christine Huey, left, Leanne O’Grady, middle and Joslynn Dieno, right, swam across Skaha Lake last August to raise money for the ALS Society of B.C. The teens started the charity swims four years ago and have raised close to to $4,000.

Photo credit Eric J. Wilson, Penticton Western News
AT ANY COST, PRICE OF LIFE IS WORTH IT

What are two years of life worth $100,000? $200,000? More? Less?

This is close to a question I ask myself nearly every morning. I like to think that I would do this whether I jump up at dawn’s first glorious breath, as I’m sure most of you do. Or, like me, you lie there until someone hauls your carcass out of bed.

Everything has a price, right? Well, the answer can’t be put in monetary terms.

Ask someone who has just buried a loved one what he or she would give to have that person back for a day, a week or even an hour.

This issue, what is your life worth, holds special meaning for me. It’s been two years since I drew a breath. That’s right, my life, as defined by the biological standard of respiration, the act of exchanging oxygen for carbon dioxide, has been turned over to a portable ventilator. Roughly two years ago, I was in a hospital, where doctors performed a tracheotomy and hooked me up to a ventilator. The vent pumps 800 milliliters of air into my lungs 12 times a minute, for 24 hours a day. For you math geeks that’s 720 breaths an hour, 17,280 a day, 6.3 million a year.

The vent does what my diaphragm cannot. It acts as a bellows by pushing air into my lungs. The failure of the diaphragm is what kills most of those afflicted with ALS, amyotrophic lateral sclerosis, aka Lou Gehrig’s disease.

Roughly 80 percent of those with ALS die within five years of diagnosis. The disease attacks the neurons that connect the brain and muscle tissues. Those with the disease become paralyzed. I was diagnosed with ALS nearly 11 years ago.

And although there’s no effective treatment and no cure for ALS, advances in medical technology have made its symptoms more bearable.

Many of these advances have come about in microprocessors and microswitches, which have made electric wheelchairs lighter and more maneuverable.

There are hands-free driving systems that make even quadriplegics independent operators. There is even a wheelchair that can climb stairs.

Computer technology gives a voice to those unable to speak.

Perhaps the most significant advances have come in respiratory care. In just a couple of decades, ventilators have gone from taking up an entire room, as did the iron lung machines in the days before the polio vaccine, to the portable units that weigh less than 20 pounds and fit on the back of a wheelchair.

Case in point: I am writing this column on a laptop computer that can also speak for me. It’s attached to a power wheelchair with a portable ventilator in the trunk.

But having all the technological accouterments at my disposal doesn’t mean life is easy for those around me. Keeping me alive uses a good chunk of family resources. Some of this comes from private health insurance and a long-term care policy.

Absent those insurance policies, which pay for a health aide, I don’t think I would ask my wife and sons to care for me, although they would do so without hesitation.

Taking care of a vented patient is arduous. Many nursing care facilities won’t accept vented patients.

Which brings me back to the question I posed earlier.

In the two years I’ve been on a vent, I have watched my sons grow into young men.

We have celebrated birthdays, graduations and anniversaries.

You can’t put a price on that.

By - Rich Brooks

This article was published on August 12, 2006 in the Sarasota Herald-Tribune. Rich Brooks writes a weekly column for the Herald-Tribune. Brooks was diagnosed with ALS in 1995.
ALS SOCIETY WINS 2006 MERCURY AWARD

The ALS Society of Canada has won a Silver Mercury Award for our publication Research News in the 20th Annual International MERCURY 2006/07 Awards competition. More than 900 entrants competed from 21 countries for this prestigious award honoring excellence in public relations and corporate communications.

Research News is a new publication by the ALS Society of Canada, whose purpose is to give hope to people living with ALS by providing information about ALS and neuromuscular research in Canada, the U.S., Europe and abroad.

"We are thrilled at having won the Silver Mercury Award for our Research News publication," says Bobbi Greenberg, director of communications, ALS Society of Canada. "With all the new research developments in the ALS community, we hope that our publication will continue to provide hope, resources, and information for people with ALS, their families and their loved ones."

Established in 1987, the Mercury Awards are presented by the International Academy of Communications Arts and Sciences, a 500-member group of leading practitioners in the communications field.

The awards celebrate creativity, originality, determination, functionality and innovative thinking across 290+ categories and classifications. Award recipients range from large PR firms to not-for-profit organizations, to unique individual efforts.

Research News is available online at www.als.ca/_research.aspx.

QUINTE-AREA FAMILIES GET AN ACCESSIBLE VAN

The Quinte chapter of the ALS Society of Ontario with the help of Shoppers Home Health Care is putting people living with ALS on wheels. Funding from the Masonic Lodge 150-year anniversary project is putting this initiative into gear.

The project puts a new fully accessible van in the hands of a Quinte-area family. The van is owned by Shoppers; however, ALS Ontario holds the lease and pays for the leasing costs using the $74,000 it received in 2005 from the Masonic lodgers in Belleville. The Quinte chapter is using the funds to cover expenses of the project for six years. The family who takes possession of the van is responsible for insurance and maintenance costs, and may chose to pay part of the leasing costs.

Quinte-area families caring for a person living with ALS who is using a wheelchair are eligible to apply. Families are chosen by a tribunal made up of local residents. To ensure an objective decision process, no one living with ALS participates in the tribunal.

Judy Davidson, diagnosed with ALS in November 2005, is the first participant in the project to receive the wheelchair-accessible van. Davidson’s family took possession of the van last August. The family is keeping the van for one year and can apply for a second year.

John Davidson said the new van is a real blessing for his wife, who is confined to a wheelchair and unable to speak. "It used to be a real struggle to get her in and out of our car and it got to the point where she didn't want to go out anywhere, but with the van, it's very efficient and not much of a struggle," he says.

Shoppers sees the opportunity to provide a van as a testing ground for future projects of this kind. If the project is successful, there may be more accessible vans available to families. Both the staff of ALS Ontario and Shoppers are co-operating to make life better for people living with ALS and their caregivers.

The Quinte-area transportation project also provides funding to people living with ALS who incur unexpected repairs on their own vehicles and helps them pay for community transit expenses.
RESERVE THESE DATES

National Hospice Palliative Care Week - May 7 - 13. For more information please visit: http://www.chpca.net/events/nhpc_week.htm

People in Motion - This show for persons with disabilities, seniors with special needs and professionals working in related areas features a plethora of exhibits which include adapted vehicles, mobility aids, rehabilitation services, home health care products, etc. It will be held in Toronto at the Queen Elizabeth Building, Exhibition Place on June 1&2. Admission is free. For more information call 1-877-745-6555.

Frontotemporal dementia in ALS - The second international research conference will be held from June 10 - 13 at the Best Western Lamplighter Inn in London, Ontario. The event is sponsored by the ALS Society of Canada; The ALS Association; ALS Society of (Windsor) Essex County, and The Michael Halls' Endowment. For more information and to register please visit www.ftdalsconference.ca.

ALS Strategies for Quality Life and Quality Care Symposium - The ALS Societies of Canada and Alberta will host this symposium in conjunction with the 42nd annual scientific meeting of the Canadian Neurological Sciences Federation at the Shaw Centre in Edmonton. The symposium will feature full-day interactive sessions and will be of interest to people with ALS, caregivers, health-care professionals, neurologists, physiatrists, and community support agencies. For more information, please visit www.als.ca.

The Canadian Neurological Sciences Federation Annual Congress will be held June 19 - 22 in Edmonton at the Shaw Conference Centre. For more information please visit: http://www.ccns.org/ccns_information/events/annual_meeting/general_info.html.

On June 19&20, the 4th Annual ALS Client Services Conference will take place at The Courtyard Marriott in Edmonton. A networking reception and dinner on Tuesday evening will be followed by a day-long workshop on Wednesday geared to learning and sharing information that will positively impact our collective ability to meet the service needs of people living with ALS. The conference will be of interest to clinic staff and ALS Society client services staff and lead support service volunteers across Canada. For more information, please visit: www.als.ca.

Go Jays Go - The Toronto Blue Jays will be playing the New York Yankees on August 7 at the Rogers Centre in Toronto. A limited number of seats have been set aside at reduced prices for the ALS Society. For every ticket sold, a portion will be given to ALS Ontario. Ticket prices are $30 (normally $44) for field-level bases or Club 200 baselines. For more information contact Paul Rabeau at 416-341-1670.

RESERVE THESE DATES

NEW DVD GIVES FAMILIES CONFIDENCE IN FEEDING TUBE DECISIONS

Managing nutrition in ALS is important at all stages of the disease. Making a decision about whether or not to take in nutrition through a feeding tube is something each person with ALS will face. However, the decision to choose a feeding tube is often daunting and confusing for the person living with ALS, friends and family.

Nutritional Lifeline: the feeding tube decision, a new DVD, focuses on all aspects of decision-making regarding feeding tubes, feeding tube insertion procedures/operations, and care and maintenance of the feeding tube once it is in place.

A sample of the 26-minute DVD can be viewed at http://www.simplifiedtraining.com/tools/nutritional_lifeline_sample.asp. Copies are available for $99 (U.S. funds) and can be ordered online or by calling 1-800-344-6681. To receive a 10 per cent discount, please quote discount code ALS123C156TI when ordering.
SURVEY RESULTS ARE IN

The results of the 2006 Coast to Coast survey are in, and the news is good. The survey, which appeared in the Summer 2006 issue of Coast to Coast, was the first in the publication’s history. Results showed that readers are overall satisfied with the content of the newsletter, and feel that Coast to Coast contains "just the right amount of technical/scientific information." They also find the articles "interesting and informative."

The cover story, Research Updates, and New Technology sections were among the most-read items in the publication, with articles about people living with ALS and Upcoming Events not far behind. Provincial/Society News and the Message from the Chair of the Board and President & CEO also ranked high on the list.

Readers were interested in knowing more about ALS clinic news and new ALS researchers. Several readers requested more articles about people living effectively with ALS. These requests will be taken into account for future publications.

A third of the survey respondents shared their issue of Coast to Coast with a friend, family member or colleague, and almost half of the respondents have been reading Coast to Coast for more than four years. Most ranked the newsletter as "very important", and were equally satisfied with the look and layout of the publication. "I like the format of the latest one, and it has lots of news" reports one reader, "the publication has improved over many years".

Other comments from Coast to Coast readers include:
• "That we are given ongoing research information is encouraging. This helps to make our donations worthwhile."
• "Research and technology updates are very interesting. I have friends who had friends who suffer from ALS - that's why I am a supporter. We must find a cure for this devastating disease!"
• "It gives one hope that results will be achieved someday."
• "Keep up the good work!"

Thank you to all the respondents. The Coast to Coast survey results will help us continue to provide up-to-date news and information regarding scientific advancements in the fight against ALS.

Many respondents indicated a wish to receive the newsletter electronically. If you would like to receive your copy of Coast to Coast by e-mail, please contact bg@als.ca.

DEVELOPING METHODS FOR EARLY DETECTION OF NEUROLOGICAL DISORDERS

Neurodyn Inc., a Canadian biotechnology company, is working to develop and market products for early detection and treatment of neurological disorders caused by environmental neurotoxins. The purpose of this project is to further develop the patent-pending animal model of human neurodegenerative diseases including ALS, Parkinson’s and Alzheimer’s. With total estimated costs of approximately $2.3 million, this project will receive up to $1.5 million from the Atlantic Innovation Fund over a three-year period.

Founded by University of British Columbia ALS researcher Chris Shaw, PhD, and Ken Cawkell, a partner with Cawkell Brodie Glaister LLP Business Lawyers in Vancouver, Neurodyn Inc. is expanding its research and development activities in Charlottetown, PEI, at the Industry Partnership Facility in the Institute for Nutrisciences and Health.

Explaining how the company came about founder Chris Shaw, explains, "Our work with the model of the Guamaninan form of ALS showed that we could identify a neurotoxin that was causal to motor neuron loss. The fact that we could reliably induce motor neuron death with a novel neurotoxin suggested that this model might be useful for testing of potential therapeutics for ALS. It also suggested that if we could model the stages of the disease, we could determine where therapy might be most effective, if such therapy could prevent progression, or even reverse the course of the disease. In turn, having an identified molecule meant that we could reverse engineer the problem to seek out susceptibility genes that might confer greater risk for some individuals. What had emerged were potentially enormous benefits for clinical studies but to take this step we needed money and the best way to leverage the necessary funds was to find some sort of mechanism that would allow a partnership between academic research and commercialization by the private sector. From this realization, Neurodyn was born."
BOOK REVIEW: DYING WAS THE BEST THING THAT EVER HAPPENED TO ME

Practicing physician Dr. William Hablitzel, former firefighter-paremedic and associate professor of clinical medicine at the University of Cincinnati College of Medicine presents a series of true stories celebrating life, love, and hope in his new book, Dying Was The Best Thing That Ever Happened To Me: Stories of Healing and Wisdom Along Life’s Journey.

In this book, Hablitzel explores the positive side of illness and death in a way that demonstrates the good things that can come as a result of uncertainty. Hablitzel focuses not only on spiritual awareness, but on the importance of friends, family, and loved ones as we travel the journey of life. The stories woven by Hablitzel's patients stress the importance of living in the moment, and escaping the ties of the past. They teach us to cherish the present while abandoning our unrealistic and often disappointing expectations for the future.


NEW WEB SITE CONNECTS PEOPLE WITH ALS WORLDWIDE

A new web site entitled, patients like me has created an interactive, online community whose purpose is to connect patients, doctors, researchers, organizations, and businesses dedicated to making a difference for people with medical illnesses and their health. The aim of the web site is to allow people with ALS to collaborate and share information on disease history, management, treatments, and outcomes.

The web site lets users create a unique user profile where they can share personal stories and insight while maintaining a personalized network of support via the online community. Discussion boards allow for people with ALS to ask questions, post and share useful information, and talk about disease progress and maintenance.

Patients like me can be found at: http://www.patientslikeme.com/

The Newfoundland and Labrador Conservation Officers Association has made the ALS Society of Newfoundland & Labrador its charity of choice. At their annual fundraising event proceeds will be donated to the society. This yearly event is in memory of conservation officer Bert Weir who lost his battle with ALS in 2004. Left to right is conservation officers Charles Gaulton and Maureen Ivany presenting the cheque to unit director ALS Society of Newfoundland Peter Puddester and executive director of ALS Newfoundland Cheryl Power.
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.