To register for the WALK for ALS, or to pledge a walker, visit als.ca.

Three letters that change people's lives. Forever.

ALS

Zack Werner is adored by the fans of the wildly popular Canadian Idol series, but what the Idol judge would most like Canadians to notice about him are his well-worn running shoes. They've seen action in the WALK for ALS – in fact, this year marks his second year as National chair and spokesperson for the Walk. In 2006, $2 million was raised in 80 communities, and in 2007, organizers hope to exceed the $2 million mark in events that will be held from coast to coast beginning in May.

"The Walk has a mobilizing effect on the individuals who participate – it provides the means for people who have ALS and their loved ones to help build awareness of ALS, and to connect with others who have been affected by the disease," says David Cameron, president and CEO, ALS Society of Canada.

"This disease can be very isolating," says Mr. Werner. "To come together for an event like this, to be able to say we are working toward something hopeful – that we have all shared in this tragic circumstance – can really provide a sense of empowerment and hope for the future."

Mr. Werner's father died of ALS 10 years ago, a week before Zack Werner's eldest daughter's first birthday. "He was a tower of strength in our family, and it took me a very long time to come to terms with his loss. We just coped through that year, and then he passed. It was so difficult for everybody."

At the time, Mr. Werner says that he didn't feel he had the emotional strength to commit himself to becoming part of the ALS community. That experience is common to ALS families, and according to Dr. Lorne Zinman, a neurologist and clinical ALS researcher at Sunnybrook Health Sciences Centre in Toronto, is one of the reasons that raising money for research is so important. "Many of us consider ALS an orphan disease. There are other diseases with similar incidence rates that receive much greater research funding. Because in most cases ALS is a severe, rapidly progressive disease (patients usually die within two to five years of diagnosis) and the care burden on families is so devastating, we lose people who could advocate for greater awareness and research funding."

In 2006, Mr. Werner attended the ALS Walk in the small town where he and his family live in southeastern Ontario. "I met a man with ALS, in his late 30s. I saw him and his family and the circumstance that they were in – and I saw what it meant to my kids and to our community to be part of that circumstance. People suffering from this disease are still alive – they are still part of the community and deserve all the care and attention they can get, to make their lives as fully functional as possible.

PHOTOS: ALS

Zack Werner (top, at right) national chair and spokesperson for the WALK for ALS, visits Roger Camara, ALS patient, and Christina Clark, House Manager at the Brummitt-Feasby ALS House in Winnipeg. Walkers in communities across Canada raise money for ALS research, client care and services.

"Seeing this man struggling to maintain his family relationships and be part of the community was a reminder of how critically important fundraising is. In the 10 years since my father's death, there has been no definitive progress in the control of this disease," says Mr. Werner.

Dr. Janice Robertson, a Canada Research Chair in the Molecular Mechanisms of Amyotrophic Lateral Sclerosis, is a Toronto scientist whose research has been supported in part by funding from the ALS Society Walk. "We want to find a treatment for ALS. But to do that, we need to understand how the disease operates."

Dr. Robertson and Dr. Zinman, along with their research teams, are developing a tissue bank that will greatly advance research capability, and have made a number of discoveries in terms of understanding basic biology of the disease. She and other researchers are also working toward an earlier diagnosis for ALS.

This and other promising research underway all require ongoing funding, which remains a daunting challenge. That is why the Walk is so important to ALS research in Canada. Forty per cent of the funds raised through the WALK for ALS goes to the ALS Society of Canada in support of ALS research developments. Of the $1 million of research funding targeted for 2007, $575,000 will be generated by the 2007 Walk.

Sixty per cent of the funds raised stay with the provincial ALS societies to help with client care and services.

"It isn't a sexy disease," says Mr. Werner. "It's not cancer, a disease that reaches everybody. But the people who do get this disease deserve our attention and our assistance. One of the ALS Society's messages is "What would you do while you still could?" This is something we can do. And if we don't take the time to stop and pay attention to neurodegenerative disorders now, ALS will continue to be an immediate death sentence." ■

The ALS Society of Canada would like to thank the national sponsors of the WALK for ALS: Canon (Gold sponsor), Hbc (Gold sponsor) and Phillips, Hager & North (Bronze sponsor).

What you should know about ALS

ALS has no known cause, no cure and no effective treatment. "This is a disease we almost cannot comprehend," says ALS Society president and CEO David Cameron. "As a Canadian, when you see your doctor, you have every expectation of a drug or a surgical procedure that gets you well. But when you're diagnosed with ALS, there is no good news. In many respects, this disease remains as fatal and little understood as it was when it was discovered in the 1800s."

Amyotrophic lateral sclerosis (also known as Lou Gehrig's disease) is one of the most devastating neurodegenerative diseases, affecting almost as many people as multiple sclerosis. People with ALS become progressively paralyzed due to degeneration of the upper and lower motor neurons in the brain and spinal cord, and usually die within two to five years, unable to breathe or swallow. (Along with ALS, neurodegenerative diseases include Alzheimer's disease, Huntington's disease and Parkinson's disease.) According to the World Health Organization, neurodegenerative diseases are predicted to surpass cancer as the second leading cause of death in Canada by 2040.

"It's a disease that bankrupts families emotionally, physically and financially," says Mr. Cameron. Children of ALS patients are often isolated by it, as the person who's ill requires all of the care and attention their spouse is capable of providing. "We're always working to provide support to these families," says Mr. Cameron.

The primary mandate of the national ALS Society is raising money to find a cure, but the organization also supports the efforts of provincial ALS Societies in their delivery of programs and services to families and individuals with ALS. "Our primary mandate is the creation of hope," says Mr. Cameron, "and the only hope out there is research. Pending the cure, our aim is to help improve quality of life for those individuals who are living with the disease."

Service delivery expands

Assisting provincial partners

In 2005, the ALS Society of Canada launched the Service and Education Enhancement and Development (SEED) Grant Program. Its purpose: to provide provincial ALS societies with an opportunity to receive financial assistance to expand service delivery capacity, or implement new projects, activities or innovative approaches to outreach, benefiting currently underserved members of the ALS community. This peer-reviewed competition will grant up to $100,000 in assistance in 2007.

The SEED program is a capacity-building program funded by ALS Canada for the benefit of the 10 provincial societies, and is designed to improve the quality of life for people living with ALS. Examples of projects underway include initiatives that

See **Seed Program** ALS2

Research progresses on crucial fronts

Building for tomorrow

During a three-day Toronto conference in March, from very early morning until after midnight, scientists and clinicians from across Canada met to share their research on ALS.

For people who have ALS today – and those who will be diagnosed in the future – the work being done by this talented, dedicated group of researchers represents their best hope. But while the research that is taking place in Canada is promising, it is tackling a complex, mysterious disease.

Denise A. Figlewicz, director of research, ALS Society of Canada, says, "I think we realized sometime in the last seven or eight years that progress will be multi-factorial. The exciting findings being reported seem to be on quite different topics, but they are probably all crucial." In fact, current ALS research work includes study

See **Research** ALS4

INSIDE:

WALK for ALS

www.als.ca

Dr. Christopher Shaw,

Professor, University of British Columbia

FOCUS: Environmental toxins

UBC professor Christopher Shaw's pursuit of possible environmental factors for ALS has taken him to the far reaches of the planet. Most of Dr. Shaw's work involves cycad, a plant that contains neurotoxins thought to trigger ALS. During the 1940s and '50s, there was an epidemic of ALS-PDC during a period when cycad seeds were a diet staple among native Guamanians.

"Naturally," says Dr. Shaw, "we believe that these are universal neurotoxins able to induce many of the (non-familial) forms of the disease. Such neurotoxins are found in other plants, just not in the extremely high concentrations found in cycad. However, there are other sources of such sterol glucosides: bacterial infection and self synthesis, to name only two."

If environment proves to be a causal feature of ALS, and the molecule(s) that cause the disease can be found outside the body, there may be other sources besides cycad that can be responsible for triggering ALS. "We have isolated several novel neurotoxins, now identified as sterol glucosides, and have examined their mechanisms of action leading to neural cell death," says Dr. Shaw. "In addition, we have devised behavioural tests to measure motor, cognitive and sensory (olfactory) function in concert with emerging changes in cellular morphology and biochemistry. Our work has successfully mimicked all crucial aspects of the human disorder and is predictive of others."

als*411*: helping children cope

When a parent has ALS, children are often left to cope with their feelings largely on their own as the family focuses on the needs of the person with ALS.

Through the ALS Society of Canada's als*411* program, these children have a resource to learn more about ALS and how the disease may affect their lives. The website (als.ca/allforkids) is available in French and English, and provides easy-to-read resources, links to other sources of information, suggestions about ways to cope, and resources for parents to help them talk to their children about ALS.

For many kids visiting the site, however, the most powerful experience is reading the personal stories shared by others who have survived the loss of a parent to ALS.

Tracy was 12 when her dad was diagnosed in 1997. "Our parents told us that we were hoping he had multiple sclerosis (MS)," says Tracy. "One day after returning from the hospital, Mom told us the doctors said Dad didn't have MS. I knew that meant he had ALS and that he would die."

Although Tracy is now studying at the University of Western Ontario to become an audiologist, she volunteers with the ALS Society as often as her studies allow. "It's a way for me to turn my experience with ALS from a negative into a positive. I plan to work as an ALS volunteer for the rest of my life, sharing whatever skills I can."

She sees als*411* as a valuable resource for the children and young adults going through an experience similar to hers. "When my father was diagnosed, it seemed too complex to understand. Anytime a doctor or nurse talked about it, they used terms like motor neurons and synapses – the disease was a big, scary thing that seemed beyond me."

PHOTO: ALS

Families affected by ALS can take comfort in the support offered by als*411*, a bilingual web-based resource that offers information, suggestions on how families may better cope, and resources to help parents discuss ALS with their children. For more, visit als.ca/allforkids.

Having access to information in terms they can understand can help kids feel more equipped to cope with the disease's progression. "It helps kids feel like they're part of their family," says Tracy, "rather than feeling isolated by ALS."

Given the opportunity to speak to children of ALS patients today, Tracy says she would advise them to be open with their emotions. "Don't feel bad that you're scared – don't feel you have to seclude yourself away. Understand that your parent hasn't changed on the inside – they still want to be talked to and treated as your mom or dad. And if you feel lost or don't understand something, there are people who are willing to help." ■

Caregiver profile, British Columbia

One family's triumphs and struggles

Lisa Richardson, 28, should be planning a career move or starting a family, and her mother, Lena Nilsson, 57, should be out running her favourite trails with her friends or bouncing a grandchild on her knee. Instead, the elder of the two Vancouver women is imprisoned in a body incapable of voluntary movement – save in a single thumb – due to ALS, a degenerative neurological disease. Mrs. Richardson has temporarily given up a marketing career to devote her days – and many nights – to caring for her mother.

"It's beyond a full-time job," Mrs. Richardson says. A nurse comes in during the day, but even getting Mrs. Nilsson out of bed and settled into a chair is a grueling, two-person task that takes 30 minutes. Then there's equipment – a feeding tube, breathing tube and respirator – to clean and maintain, supplies to order, doctors' appointments to organize…the list goes on. So while Mrs. Nilsson's whole family pitches in, her daughter's caregiving duties fill more than 40 hours a week.

Things were very different three-and-a-half years ago. "My mom was extremely active, very fit and outgoing," Mrs. Richardson recalls. Then Mrs. Nilsson's speech became slightly slurred. Eventually, she was diagnosed with bulbar ALS. Within six months, she had lost her voice, communicating via a computer program that converts typescript into spoken words. Otherwise, for two years, life went on unchanged – she continued operating the family business and even ran a five-km. race. Since last July, however, the disease has progressed quickly.

Nonetheless, both Mrs. Nilsson and her daughter retain a glass-half-full outlook.

PHOTO: MIKE WAKEFIELD, NORTH SHORE NEWS

Just three-and-a-half years ago, Lena Nilsson (left) was a vibrant, physically active 54-year-old. ALS has shattered her life and left her dependent on the aid of caregivers, including her daughter Lisa Richardson.

Before ALS stole her voice, Mrs. Nilsson told her family she felt some good had come from her diagnosis, because it brought them closer together. Today, despite only being able to signal thumbs-up or thumbs-down, she manages to dissemble about her age (she tried shaving a year off for this article) and enjoys visiting with friends and family, including her son's two young children. For her part, Mrs. Richardson feels fortunate she's financially able to temporarily give up paid work. She's also having fun honing her marketing skills while fundraising for ALS research and services. She and her husband organize the ALS Adventure Challenge, an outdoor sporting event the couple launched in 2004.

Mrs. Richardson is haunted by the fact her smart, sociable mother remains aware of everything, but has great difficulty communicating – it can take 10 minutes of questions just to figure out Mrs. Nilsson's distress stems from a pinched arm. "It's hard on me, but it's much harder on her," Mrs. Richardson says. "I can't imagine not doing this for my mom." ■

Tribute

Elizabeth Grandbois

Faced with the diagnosis of a fatal degenerative disease, many of us might quietly withdraw from the world – but that's just not Elizabeth Grandbois' style. Instead, the former nurse became a public speaker and phenomenally successful concert organizer/fundraiser dedicated to raising awareness about ALS, and improving the lot of Canadians affected by it. In a little more than seven years, she has raised more than $2 million for ALS research and support services through Elizabeth's Concert of Hope, a concert series featuring homegrown Canadian talent.

Originally conceived as an annual event, Elizabeth's Concert of Hope was launched in 2000, in Ms. Grandbois' hometown of Hamilton, Ont. With the help of a cadre of dedicated volunteers, she and the late Bill James (who was also stricken with ALS) enlisted the aid of people in Canada's entertainment community, including Ian Thomas, Tom Cochrane and Murray McLauchlan. Last year, Ms. Grandbois decided to take the show on the road to increase awareness of ALS. Sponsored by Tim Hortons, Via Rail and BBDO Toronto, Elizabeth's Concert of Hope was staged in seven cities – each with its own unique musical line-up – from coast to coast. A second Vancouver concert is planned for this fall.

According to David Cameron, president and CEO of the ALS Society of Canada, the concert series, and accompanying media attention, has gone a long way to raising the profile of the little-known disease, for which there is no recognized cause or treatment. Mr. Cameron credits much of the success of Elizabeth's Concert of Hope to its namesake's ability to inspire others. "Elizabeth Grandbois is an individual to whom very few people, if any, can say 'no'," he says with a wry smile. "She demonstrates what one person with passion can do to change something that seems insurmountable." ■

Volunteer profile, Timmins, Ontario

Dominique Cadeau

On June 9, Dominique Cadeau will be leading the Timmins WALK for ALS. As with many of the participants in Walks across the country, for Ms. Cadeau, the battle is personal. She has already lost five family members to the disease; many more are at risk due to a mutant gene (SOD1) that causes familial ALS. An aunt currently has ALS; her mother has been diagnosed but does not yet have symptoms. (While most cases of ALS are not inherited, it is estimated that approximately 10 per cent are familial.)

Dominique's brother Durwin, who was only 26 when he died of ALS, inspired her to become a Walk co-ordinator. She chose Timmins because it was his hometown, and the city where he received the majority of his ALS care.

"We have a great team of family members and friends that participate in Walk locations all over Ontario…Since Timmins has never had a Walk, I thought it would be a great opportunity to raise awareness and funds in the northern communities. It will also be beneficial in helping find a cure for this disease and to support other families living with ALS," says Ms. Cadeau. ■

Provincial societies gain

Seed Program from ALS1

will allow the ALS Society of Newfoundland and Labrador to provide help through home visits to ALS families. Manitoba used its SEED grant to offer the first ALS conference in Manitoba to educate healthcare professionals about ALS and to improve quality of care throughout the province.

The ALS Society of Quebec Volunteer Home Visit and Telephone Support Program was provided with funding to help recruit, train and match volunteers to provide visitor services and support phone calls.

The ALS Society of British Columbia received funding for Team ALS BC, a portable training program aimed at training volunteers online. ■

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www.als.ca

Dr. Jean-Pierre Julien,

Canada Research Chair in the Mechanisms of Neurodegeneration, Université Laval

FOCUS: Transgenic mouse models, inflammatory phenomena

By seeking to discover and demonstrate the molecular and cellular mechanisms of ALS that contribute to the loss of motor neurons, Jean-Pierre Julien's research is leading to new therapeutic targets and the development of more effective treatments for neurodegenerative diseases.

"We have known since 1993 that mutations in the superoxide dismutase gene are responsible for 20 per cent of the cases of ALS in families," says Dr. Julien. While noting the causes of the disease remain unknown, he adds, "It is thought that multiple genetic factors are probably implicated." He says recent studies suggest that abnormal accumulations of the proteins that form the cytoskeleton may contribute to neurodegeneration. While there is still no therapy to halt the disease, Dr. Julien's laboratory recently demonstrated that a combination of three medications was able to significantly impede the progress of ALS in laboratory rats. This discovery will make it possible to soon develop clinical trials of this pharmacological "cocktail" for human patients suffering from ALS.

Research is the only hope

SEAN McCONKEY
Chair of the Board of Directors, ALS Society of Canada;
Associate Partner, Director, Human Resources GTA
Deloitte & Touche LLP

ALS is a devastating neuromuscular disease affecting many more people than the approximately 2,500 to 3,000 Canadians living with it today. Death typically occurs from respiratory failure within two to five years of diagnosis. There is no known cause and no cure yet. Research is our only hope.

The ALS Society of Canada, founded in 1977, is the only national voluntary health organization dedicated solely to the fight against ALS and support for those with ALS. With more than $1 million in research funding committed for 2007, we continue to support our vision – finding a cure for this fatal disease.

Funding ALS research is the central mission of the Society. We also strive to raise awareness about the disease and to support provincial ALS societies in their provision of quality care for persons living with ALS.

As ALS Canada Chair, I continue to ensure that the Society is governed in a way that honours and supports our mission and vision.

ALS Canada has a partnership agreement with the 10 provincial ALS societies that provide equipment, care and support services to people affected by ALS. The federation of Canadian ALS Societies provides a framework through which we work together and share responsibilities, allowing for an efficiency not often seen in national health charities.

Our main research program, the Neuromuscular Research Partnership (NRP), funds health research through operating grants in the area of neuromuscular diseases with a mandate to find a cause, treatment options, and eventually a cure for ALS. Our partnership with the NRP is just one of many research programs that ALS Canada has in place to help combat ALS.

The NRP, in collaboration with Muscular Dystrophy Canada (MDC), and in partnership with the Canadian Institutes of Health Research (CIHR), has funded more than $21 million in research since its inception in 1999. In 2007, the NRP will jointly invest an additional $1.7 million in research on neuromuscular disorders.

As a founding member of the International Alliance of ALS/Motor Neurone Disease (MND) Associations, ALS Canada will host the 18th International Symposium on ALS/MND in Toronto, December 3 to 5, 2007.

ALS Canada offers numerous awards and scholarships to help draw young researchers to the field of neuromuscular research and seed the future for further research developments. These awards are given using a peer-review process to ensure that research funds are allocated where they will have the most impact.

Two of the most recent awards offered are the Doctoral Research Awards, in partnership with CIHR, where two young researchers were granted a maximum of three-year support grants in the amount of $21,000 per year, and the Tim E. Noël Fellowship in ALS Research, to fund an annual grant of $55,000 for up to three years.

Through the efforts of leading scientists in Canada and around the world, our understanding of ALS has increased dramatically. Combined with the advances in neurology, effective therapies and a cure are within reach. ■

Join us in our fight against ALS, and contribute to the cause by calling us at 1-800-267-4257 or visiting our website (als.ca).

PHOTO: ALS

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

Volunteer profile, Edmonton, Alberta

Chris Yates

When Chris Yates of Edmonton was approached in 2001 about initiating the WALK for ALS in Alberta, he didn't hesitate. Before long, his wife Teddy was working at his side, and their daughter Heather had taken on administration and technical duties in the tiny ALS Society office.

Across Alberta, the Walk became an instant success due to his leadership, and by 2002, he sat on the provincial ALS Society board, serving as a liaison between Alberta regions. Described by fellow volunteers as having a wonderful sense of fun and humour, Chris and Teddy rolled up their sleeves and pitched in when it was time for the Society to move to larger offices; Heather lined up furniture donations.

In 2003, Chris Yates retired from active duty, but is still considered an invaluable advisor to the Alberta ALS Society today. As a direct result of his early involvement, the Alberta North Region ALS Society office now serves more than 100 clients and families per year, and in 2006 brought in nearly $250,000 from the Walk and other donations that spring from increased awareness of ALS in the region. ■

Dr. Heather Durham,

Director, Neurotoxicology Research Laboratory, Montreal Neurological Institute and Hospital

FOCUS: In-vitro models

At the Montreal Neurological Institute, Dr. Heather Durham's lab is advancing understanding of the mechanisms responsible for ALS. She and her colleagues have developed a model for studying the familial forms of motor neuron disease in tissue culture, in which the mutant proteins responsible are expressed in motor neurons, the cells most affected in ALS.

Using these primary culture models and transgenic mice, Dr. Durham's laboratory is linking the vulnerability of motor neurons to the way in which they respond to stress and deal with damaged proteins. Her lab has identified abnormalities in the processing of mutant superoxide dismutase that likely contribute to the pathogenesis of ALS. They are showing how excitation by the neurotransmitter glutamate impairs the ability of motor neurons to process mutant proteins and how this likely contributes to the course of ALS. They are searching for treatments to help motor neurons cope with both the stresses of normal living and the additional challenges imposed by disease.

As additional genes responsible for motor neuron diseases are mapped, Dr. Durham's lab is establishing culture models to identify mechanisms in common that could be relevant to sporadic ALS as well and serve as targets for therapeutic development.

www.als.ca

Dr. Guy Rouleau,

Canada Research Chair in Genetics of the Nervous System, Université de Montréal

FOCUS: the biological basis of diseases of the nervous system

At the Université de Montréal's Centre for the Study of Brain Diseases, director Guy Rouleau has amassed a substantial database of French-Canadian ALS patient DNA. The purpose: by examining the limited genetic diversity of this population, Dr. Rouleau and his colleagues hope to identify genes that predispose for ALS, and advance understanding of the causes of diseases of the nervous system and the development of new treatments for them.

In addition to contributing to the mapping, isolation and characterization of many genes, and the use of techniques such as gene expression and nano-imaging to uncover the function of proteins affected by disease genes, Dr. Rouleau is now working 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.

Looking further afield for answers, Dr. Rouleau is also carrying out an epidemiological analysis to study how the environment influences disease symptoms and severity.

Quality of life

Achieving optimal care for ALS patients is a complex feat, but advances in care and new approaches are making a difference

In Edmonton, the University of Alberta ALS clinics are multidisciplinary centres dedicated to the care of patients with ALS and other motor neuron disorders. Dr. Sanjay Kalra, a neurologist and clinic co-director, says, "Instead of coming to a private office to see a doctor, and then receiving a series of referrals, our patients come for a few hours and see the different practitioners they need. We can all communicate and make decisions together – it speeds up both decision-making and implementation."

Health professionals on staff include neurologists, clinical nurse specialists, clinic co-ordinators, physical medicine and rehabilitation specialists, speech language pathologists, senior respiratory therapists, research co-ordinators, physicians specializing in respirology, and education and support services through the ALS Society of Alberta. Diagnostic services, education, treatment, rehabilitation and research are conducted at the University of Alberta Hospital, the Glenrose Rehabilitation Hospital, the Misericordia Hospital and the Cross Cancer Institute.

"Our main strategy," says Dr. Wendy Johnston, neurologist and clinic director, "is to look at each ALS patient as an individual, within the context of their family or social network. You can't provide cookie-cutter care. People with ALS make a lot of hard choices, informed by their spiritual beliefs and their past experience. Patients with similar symptoms may make very different choices about their management. Our definition of quality of life is 'it is whatever the patient says it is."

In the more than 15 years since she launched her first ALS clinic, disease-specific care has not advanced as much as technology, says Dr. Johnston, but technological advancement has improved quality of care delivery. "People can accept a higher level of care because it is not so intrusive – machines are smaller and quieter."

The isolation experienced by patients has also been alleviated by technology. "People may become both physically limited and limited in their ability to communicate – but even those who live in remote communities can feel supported by others through the Internet. People can avail themselves of support and information and feel more in control of their own care."

Other challenges for ALS patients include nutritional difficulties; over the past decade, placement of feeding tubes has become much safer, allowing for more comfortable, high-quality nutrition. Better non-invasive strategies for ventilation have also developed. Strategies such as assisted cough and lung volume recruitment exercises can help keep the airways clear.

"I'd like every patient with ALS to have access to the treatments that we know make a difference," says Dr. Johnston. "Across Canada, this is still a challenge. In part, it's our geography, but it is also ignorance."

Patients attending multidisciplinary ALS clinics have an improved prognosis, says Dr. Kalra. "Their median survival is extended by 7.5 to 10 months."

"We didn't have a clinic here six years ago," says Dr. Johnston. "We've built it person by person; we've slowly built it up to clinics working in three sites. We're still working toward our goals, but in six years we've managed to expand to offer a wide range of services. It's doable – this is what's possible, across the country." ■

June is ALS Awareness Month in Canada

June is ALS Awareness Month in Canada. Various activities will be held across Canada in recognition of ALS Awareness Month. Flower days are held nationwide. The blue cornflower is the symbolic flower of hope for ALS. The majority of the WALKs for ALS will take place in close to 75 communities across Canada this June.

The blue cornflower was chosen as the national symbol of hope for ALS because of its fragile appearance yet hardy nature. Like the cornflower, people living with ALS show remarkable strength in coping with a devastating disease.

The cornflower grows wild across most of Canada and is long-lasting with striking blue, star-like blossoms.

Profile, New Brunswick

A family affair

Mike Smith is a father, cherished husband and former member of the Canadian military. He is both beloved older brother and best friend to his younger sister, Carrie Smith. And in 2005, at the age of only 33, immediately following a happy reunion with his family after an overseas military mission, Mr. Smith was diagnosed with ALS.

PHOTO: ALS

The Smith family of New Brunswick (Lisa, Mike and their twins Victoria and Johnny) is among the many Canadian families dealing with the ravages of ALS. Their experiences have motivated Mike's sister Carrie to become an ardent ALS Society supporter, joining thousands of Canadians across the country who are helping fight this disease through fundraising and other efforts.

When Carrie Smith learned of the diagnosis, she decided she would do everything she could to help. This year is her second as walk co-ordinator of the Mike Smith Fund WALK for ALS in Moncton. In 2006, her team raised $47,000, more than double the funds raised the previous year. (Some of the incentives she's inspired local businesses to donate for 2007 include three months at a weight loss clinic, three months of free housecleaning, a ballot for a trip to a sunny travel destination, and a key that gives eligible participants a chance to drive away with a one-year car lease.)

In addition to the Walk, she has also organized many additional fundraising events including a spin-a-thon collaboration with her local YMCA, a Women's Night Out celebration that raised almost $6,000, and a draw for a Harley-Davidson motorcycle that is slated to raise $20,000.

Mike Smith's disease is progressing. Tasks that require fine motor skills, such as buttoning his children's clothes, have become very challenging. No longer able to serve in the military, he cherishes every moment he's able to spend with Johnny and Victoria, who are now two years old. (After trying for almost eight years to have a child, he and his wife Lisa were blessed with twins, born just four days before his ALS diagnosis.)

"A person learns very quickly the value of life and what is important," he says. "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."

For Carrie Smith, awareness of the disease is an important part of finding a cure, and she works tirelessly to bring her brother's plight to the attention of the media and the public.

"Now we focus our energy on letting Mike know that we are trying our hardest to fund a cure," she says. "It is out there, and we just need a little time." ■

Profile

Newfoundland and Quebec units

When Cheryl Power's father was diagnosed with ALS in 1989, the ALS Society of Canada didn't even have a Newfoundland office. But staff with the national organization connected her with another affected family in her hometown of Corner Brook. "It all started in somebody's house, having a chat, having a cry, and we grew from there," she recalls.

Before long, the ALS Society of Newfoundland and Labrador (now one of 10 provincial ALS societies) was born. As executive director, Mrs. Power ran the organization from her home, volunteering her evenings after working all day. Back then, the operation was so small that volunteers sometimes charged equipment like wheelchairs to a personal credit card, until the cost could be recouped through bingos and card games. Today, with the support of fundraising events like the WALK for ALS, the organization has opened an office and is helping 35 people throughout the vast region cope with the disease, with services ranging from support groups to loans of equipment like hospital beds. (An item not covered through Newfoundland and Labrador's provincial health insurance, these beds can be raised at the head, allowing someone whose breathing muscles have been weakened by ALS to sleep more comfortably.)

The ALS Society of Quebec is larger – so much so it employs a full-time social worker – but provides similar services throughout la Belle Province. "We're here to provide support, information and referrals for people living with ALS and their families, to support research through our fundraising, and raise awareness of the disease through events like our Celebrity Softball Game and Walks for ALS," explains Claudine Cook, executive director of the ALS Society of Quebec. The Society also offers the loan of equipment like lift chairs, which raise the occupant into a standing position. (Quebec supplies hospital beds to people with ALS – each jurisdiction's health coverage is different.) The Society also hosts support groups for people with the disease and their caregivers, as well as informational talks featuring guest speakers – a recent example being 'Exercise and ALS.' With the help of a volunteer co-ordinator, the organization is also establishing a presence outside of Montreal, where the main office is located.

Both Mrs. Power and Ms. Cook fervently wish they could close their respective offices and throw a party to celebrate a cure for ALS. But in the meantime, says Mrs. Power, "We give people hope, we give them a shoulder to cry on, equipment, and as much support as we can. It's all about the person being able to live at home, with their family, with dignity." ■

PHOTO: ALS

Cheryl Power, executive director, ALS Society of Newfoundland and Labrador, makes a home visit to Henry Kendall, who has ALS.

Building for tomorrow

Research from ALS1

of cell mechanisms, genetic predisposition, viral or infectious agents, immunological changes and environmental toxins.

Dr. Figlewicz says that most of the field has reached a consensus that, in those cases of ALS that are not inherited (about 90 per cent), the trigger is a combination of genetic predisposition combined with some kind of insults to the neuron that stem from the individual's lifestyle. "None of this is easy to prove," she says, "and it hasn't been proven, but it is the most likely explanation for the solid but divergent data that's been accumulated to date.

While researchers work hard to identify the cause, many are also working to improve treatments and quality of life for ALS patients. "I would say that, realistically, there are promising advances that will be out there in the next five years," says Dr. Figlewicz, "because there are a lot of things about to go into clinical trials, and some of those will likely help. Our first goals are to have people live longer while maintaining as much of their normal life function as they can, and that kind of treatment is coming up. Real strides are being made."

The primary research program of the ALS Society of Canada, the Neuromuscular Research Partnership (NRP), funds health research by providing operating grants in the area of neuromuscular diseases with a mandate to find a cause, treatment options and eventually a cure for ALS. In collaboration with Muscular Dystrophy Canada and in partnership with the Canadian Institutes of Health Research (CIHR), NRP has funded more than $21 million in research since its inception in 1999.

Dr. Remi Quirion, scientific director of the Institute of Neurosciences, Mental Health and Addiction (INMHA) at the Canadian Institutes of Health Research, says, "We're very lucky in Canada to have very strong experts and clinicians in the field of ALS. It remains a very challenging issue, and we're far from being able to cure it. But we've made significant progress in the past 10 years."

"There are indications that that new treatments and drugs are on the way. We've seen significant progress from ALS research teams that have improved our understanding of the disease and the disease process – this, we hope, will lead to new therapy." ■

Dr. Michael Strong,

Professor and Co-Chair of Clinical Neurological Sciences, University of Western Ontario's Schulich School of Medicine, and Chief of Neurology at London Health Sciences Centre.

FOCUS: cytoskeleton, frontotemporal dementia

Since the early 1990s, Michael Strong's laboratory and clinical research group has researched the frontal lobe dysfunction of ALS and has contributed significantly to our understanding of neurochemistry involved in ALS. Most recently, he has pioneered research in ALS-related dementia. A $5-million gift from patient Michael Halls, who died recently from ALS, supported an endowed chair held by Dr. Strong.

In response to being awarded the 2005 Sheila Essey by the American Academy of Neurology, for seminal research into understanding the alterations in cognition in ALS that were previously unrecognized, Dr. Strong said, "This is a tremendous honour not only for me, but for the members of my lab who have worked toward understanding this devastating illness. It is also a tribute to the ALS community of southwestern Ontario, which has long supported our research."

He noted the award also recognizes the value of research into the fundamental biology of ALS, and particularly his lab's understanding of the involvement of ALS that occurs outside of the motor system and gives rise to cognitive impairments.

Assistive devices

New technologies help people with ALS continue doing things most of us take for granted

In a sense, life is the least of what ALS steals from its victims. By slowly robbing an affected individual of the ability to move and speak – while leaving the person intellectually intact – the disease strips away thousands of small things that give our lives meaning. For instance, saying 'I love you' to your spouse, or phoning your 17-year-old daughter to ask how her first week of university went.

In fact, according to Pearl Gryfe, clinical director of the Assistive Technology Clinic, a unique program for ALS patients at Sunnybrook Health Sciences Centre in Toronto, people with the disease feel the loss of spoken communication more keenly than any other. "We've done some research on this," she notes. "Communication is regarded as the greatest need, over mobility and writing."

Tammy Breton tries to convey why communication is so crucial. "You have so much inside that you want to share with people and you can't, and that can make you feel so alone," she says. A nurse in Smiths Falls, Ontario, Mrs. Breton isn't speaking in her professional capacity, or, for that matter, using her vocal cords. Diagnosed with ALS a year ago, she communicates with a small, handheld device. "I type what I want to say, and it speaks for me," she explains.

This is just one example of how technology can help people with ALS continue doing things most of us take for granted as the disease progresses. For instance, a too-soft voice – a common symptom of early ALS -- can be remedied with a portable amplifier. "That's usually quite effective," notes Frances Ezerzer, a speech-language pathologist at the Assistive Technology Clinic. Once the voice fades further, devices like Mrs. Breton's come in. These can be used as she describes, or programmed to play pre-recorded messages at the push of a button. Special attachments even make phone conversations possible.

As hand control ebbs, the situation becomes more challenging – but not impossible. "We can almost always find a way to operate a communication device," says Karen Hall, an occupational therapist with the Assistive Technology Clinic. For instance, someone who can still type, but suffers muscle weakness, can use word prediction software to cut down on keystrokes. As ALS continues its destructive march, speaking devices and computers can be operated via a mouse that responds to head movements, or a sophisticated camera system that tracks eye motion. Individuals with multiple challenges might use a single controller to operate a power wheelchair, computer and a speech generation device.

Such tools can help people with ALS make the most of the time they have left. Mrs. Breton is a case in point. While ALS forced her to give up a beloved job in Intensive Care, a supportive workplace and her speech generation device have allowed her to continue her career elsewhere in the hospital. The device keeps her connected with co-workers and friends, and enables her to converse with family members, including her grown children.

PHOTO: ALS

ALS patient and newlywed Tammy Breton communicates with loved ones, including husband Mark, with the help of an assistive device.

"I don't think most people understand how it feels to get up in the morning, and not to be able to say 'good morning' to your husband," observes Mrs. Breton, who was newly married last spring. "This great device has helped so much." ■

www.als.ca

WALK for ALS

JOIN A WALK IN YOUR LOCAL COMMUNITY

ALBERTA		
Cold Lake	Lakeland Lutheran Church	June 9
Edmonton	William Hawrelak Park	June 9
Grand Prairie	Muskoseepi Park	June 9
Lethbridge	Nicholas Sheran Park	June 9
Lloydminster	Bud Miller Park	June 10
Manning	Lion's Club Park	June 9
Medicine Hat	Strathcona Island Park	June 9
Red Deer	Little Chief Park	June 9
BRITISH COLUMBIA		
Fraser Valley	Mill Lake Park	June 16
Oceanside	Parksville City Hall Plaza	June 9
Okanagan	Waterfront Park, Kelowna	June 2
Prince George	Masich Place Stadium	June 3
Richmond	Garry Point, Steveston	June 9
Victoria	University of Victoria, Ring Road	Sept. 23
West Kootenay	Lakeside Rotary Park, Nelson	June 3
MANITOBA		
Belmont	Club Rooms, 3rd Street	June 3
Brandon	Riverbank Discovery Centre	Sept.
Gladstone	William's Park	June 9
Selkirk	Selkirk Park	June 16
Thompson	CHTM Radio Station, Cree Road	Sept. 15
Winnipeg	Assiniboine Park	May 26
NEW BRUNSWICK		
Bathurst	Tourism Centre	June 2
Miramichi	Harkins Memorial Track & Field	June 2
Moncton	Centennial Park	June 3
Saint John	Rockwood Park	June 2
NEWFOUNDLAND		
Brownsdale/Sibleys Cove	E.J. Pratt High School	Sept. 16
Burin	Royal Canadian Legion Br. 29	June 10
Clarenville	Nancy's Dance Studio	June 10
Corner Brook	Co-Op Building, Upper Level	June 10
Georgetown	Longpond	June 10
Happy Valley/Goose Bay	The Aurora Hotel, Happy Valley	June 10
LabradorCity/Wabush	Wabush Royal Canadian Legion 57	June 10
St. John's	Mews Community Centre, Mundy Pond	June 10

NOVA SCOTIA		
Cheticamp	TBD	June 16
Digby	Shore Road	Sept. 2
Halifax	Halifax Commons	June 16
Inverness	Inverness Raceway	June 16
Point Tupper	Statia parking lot	June 16
Scotchtown	4 Fortune St., Sydney	June 16
Springhill	Dr. Carson & Marion Murray Community Centre	June 16
Truro	Superstore CommunityRoom, Elm St.	June 16
ONTARIO		
Alliston	Alliston Christian Reformed Church	June 2
Barrie	Springwater Provincial Park	June 23
Belleville	Riverside Park	Sept.22
Brampton	Jim Archdekin Recreation Centre	June 9
Cobourg	Victoria Park	April 29
Cornwall	St. Lawrence College	June 9
Durham	Port Perry Fairgrounds	June 16
Halton	Bronte Creek Provincial Park	May 21
Hamilton	Hamilton Bayfront Park	June 9
Kingston	Loyalist Community Centre	June 9
London	Springbank Park	Sept. 29
Newmarket	Fairy Lake Park	June 24
Niagara Falls	Chippawa Lions Park	June 16
North York	E.T. Seton Park	June 9
Ottawa	Lansdowne Park	June 10
Smiths Falls	Royal Canadian Legion	Sept. 8
Stratford	Upper Queens Park	June 9
Sudbury	Delki Dozzi Park	June 9
Timmins	Mountjoy Historical Conservation Area	June 9
Thunder Bay	Slovak Legion	Sept. 30
Toronto	Ontario Place	June 9
Wingham	Riverside Park	June 23
PRINCE EDWARD ISLAND		
Oyster Bed Bridge	Raceway Park	June 16
SASKATCHEWAN		
Prince Albert	SAITS Campus	June 9
Regina	2180 23rd Ave.	June 2
Wynyard	Legion Hall	June 17

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?

Photo courtesy of: Duane Rollins, Wingham Advance-Times

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