BBDO CREATES TV ADS FOR ALS

The ALS Society of Canada is very fortunate to be working with BBDO Canada - one of Canada's largest and most successful advertising agencies.

ALS Canada’s national executive director David S. Cameron says, “BBDO and the ALS Society of Canada have been working together since March 2004 to develop creative that will generate awareness of ALS and help to drive donations to the ALS Society of Canada. We’re thrilled to be working with BBDO. Their senior people are working on our account and are donating their time on a pro-bona basis as they believe in our mission.”

The theme of the ads are hugging and running and the tag line to the ads is “What would you do, while you still could.”

All of the actors for the television shoot donated their time to film the television commercials. “This was no mean feat. The actors put in an 18-hour day because they wanted to do something for ALS,” says Bobbi Greenberg, director of communications at ALS Canada. The ads were shot in and around Hamilton and one of the location providers Pascor Mill Services donated its film-shoot honorarium back to ALS Canada to help fund research for this devastating disease.

BBDO is working with ALS Canada to create three television spots, print (newspaper and magazine), and interior transit to get our message across as well as rebranding of our marketing materials. The television ads (two 30-second and one 60-second spots) will air across the country in the new year. Check out the television ads on our web site - www.als.ca The ads will also air in more than 100 movie cinemas across the country commencing next spring.

Some of BBDO’s clients include: Mars, Wrigley’s, Campbell’s, Daimler Chrysler Canada, Frito Lay Canada, Bayer and Certas.

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ALS has new vision statement

The ALS Society of Canada was founded in 1977 and since then the society has grown to include a partnership with 10 separate provincial units across the country. We are a national voluntary organization dedicated solely to those living with ALS.

Our mission is to:

- Support research towards a cure for ALS
- Support provincial ALS societies in their provision of quality care for persons living with ALS
- To build public awareness of ALS and its impact

The ALS Society of Canada funds only the most promising projects reviewed by some of Canada’s top researchers. Over the years, this strategy has been rewarded with breakthrough discoveries.

Persons living with ALS include those who have ALS and their family caregivers. Through volunteers and staff from the 10 provincial societies, families living with ALS are offered practical and emotional support, referrals to services in the community and equipment.

We also provide comprehensive, accurate and timely information about ALS to those with ALS, those living with ALS, the research and health-care community, the media and our donors.

Vision Statement

At our October 2004 board meeting the board approved the society’s first vision statement which is: to find a cure for ALS.

David S. Cameron, national executive director explains, “This vision statement is reflected in everything we do at the national level. It is our raison d'être and something in which the board and staff believe and carry out in their day-to-day work. Having a vision statement provides us with the additional impetus to find a cure for this devastating disease. With the significant, recent advances made in neurology and genetics, we know that effective therapies and cure are now, more than ever, within reach.”

Medical Student Honoured for ALS Research

Kevin Harris, BSc, a third-year medical student at the University of British Columbia in Vancouver has been selected to receive the 2004 G. Milton Shy Award for his essay, “Comparison of Quality of Life, Cognition, and Capacity in Ventilator Dependent and Non-Ventilator Dependent Amyotrophic Lateral Sclerosis Patients.” Harris was honored during an awards luncheon at the American Academy of Neurology 56th Annual Meeting held April 24-May 1 in San Francisco.

The G. Milton Shy Award is presented to the best medical student essay in the field of clinical neurology.

“I was honoured to learn that I had been selected,” said Harris. “I hope that this award will stimulate others to pursue further research in this area as we all strive to improve the quality of life of ALS patients and their families.”

During the meeting Harris presented a poster based on the essay. His research assessed decision-making capacity in ALS patients, and also assessed whether or not there are changes in memory and thinking in ventilator-dependent patients.

The $350 prize also included expenses to attend the meeting and a one-year complimentary subscription to the journal Neurology.

“This novel area of study is tremendously important because ALS patients are confronted with decisions regarding treatment options throughout the course of their disease,” said Harris. “The impact of changes in memory and thinking on decision-making abilities has not been recognized in the past.”

The American Academy of Neurology, an association of more than 18,000 neurologists and neuroscience professionals, is dedicated to improving patient care through education and research.

ALS Society of Canada holds its first research forum

The ALS Society held its first research forum October 15 & 16, 2004 at the Bank of Montreal Institute for Learning, in Scarborough.

The purpose of the forum was to consult with members of the Canadian ALS research community to review and recommend priorities and direction for the ALS Society of Canada research program. Our existing research program is primarily a collaborative initiative with Muscular Dystrophy Canada and the Canadian Institutes of Health Research (CIHR).

In attendance were top Canadian researchers, and the next generation of young post-doctoral researchers - with an interest in ALS research, including those funded by the Neuromuscular Research Partnership (NRP). The NRP is a partnership between Muscular Dystrophy Canada, ALS Society of Canada and the CIHR. In this partnership, each of the three organizations contributes an equal amount agreed upon each year and combines that with other CIHR funds to support leading Canadian neuromuscular research.

David S. Cameron, national executive director of the ALS Society of Canada says, “We have funded 42 separate projects, proposed by 34 researchers in five provinces.”

The keynote speaker on Friday, October 15 was Dr. Rémi Quirion, professor and scientific director at the Douglas Hospital Research Centre - a McGill affiliated teaching hospital in Montréal and Scientific Director at INMHA, Institute of Neurosciences, Mental Health and Addiction, CIHR. Dr. Quirion discussed the importance of partnerships in the scientific research community.

On Saturday October 16, Dr. Neil Cashman, head of the Neuromuscular Clinic of the Sunnybrook & Women’s College Health Sciences Centre and the University of Toronto, and Chair of the ALS Society of Canada’s research policy committee led the group to help determine the areas of priority for research funding and to propose future initiatives and partnerships for ALS research.

Funding assistance for this event was provided by the Institute of Neurosciences, Mental Health and Addiction.
In June, ALS Canada and Muscular Dystrophy Canada (MDC) held the review for relevancy component of the Neuromuscular Research Partnership (NRP) grant competition. In a day-long session the two-member panel of ALS researchers discussed with their MDC counterparts the many grant applications that had already received a CIHR review for scientific merit. The panel ranked the grants on relevancy based upon the criteria established some years ago. Nine grants were subsequently announced by CIHR as recipients of NRP funding and the details can be found on the CIHR website at http://www.cihr-irsc.gc.ca/e/23991.html.

In June, ALS Canada was invited to sit on the steering committee of the Health Charities Coalition of Canada (HCCC), the former Health Charities Council of Canada. The steering committee's role is to reorganize the failed predecessor organization and move it into a new entity that provides value to the health-charity community in Canada. Over the summer months the steering committee met by teleconference and in late August a face-to-face meeting was held in Toronto. This meeting was a strategic planning session which identified a path forward for HCCC. It envisioned four task groups to work in the areas of access to care, pharmaceutical, tax policy, and research. Each of the four task groups is responsible for developing a set of recommendations which will be discussed with their MDC counterparts and sent to the public for comment and move it into a new entity that provides value to the health-charity community in Canada.

On October 15 & 16, ALS Canada hosted a research forum to which the ALS researchers in Canada were invited. The creation of the program was a joint effort with Dr. Neil Cashman in his role as Chair of the ALS Canada research policy committee. We secured as our guest speaker the scientific director for the Neurosciences, Mental Health and Addiction Institute of CIHR, Dr. Rémi Quirion.

CIHR provided some funding for the event. We invited each researcher to bring their brightest student along to the session and we had 15 students participate and 14 researchers from across Canada, as well as the scientific director from ALSA. The agenda dealt with the future of research initiatives and how ALS Canada can work with and support the research community. At the conclusion of the event there was a clear indication of the desire to hold a similar forum next year.

We have been approached by the producer of the documentary on Elizabeth Grandbois, “Elizabeth’s Hope”, to see if we might have an interest in purchasing the Canadian rights to the film. It is currently being aired on the PBS station in Buffalo and the audience is significant in southern Ontario and the United States. A review of the film and a discussion on the value to ALS Canada and the partner societies was had separately and with the public awareness committee. A recommendation was made to proceed to negotiate for the Canadian rights and we are in the process of doing that right now. Once secured we will arrange to have a tagline on the PBS film that provides the ALS Canada 800 phone number and our web site. Plans are underway to identify other beneficial uses for the film.

In late September we hosted a follow-up session of the Benchmarks of Excellence workshop with Linda Mollenhauer presenting for us. All of the health charities that had participated in the original program and several additional ones were invited to attend. We had a turnout of 20 participants and received positive feedback both on the content of the program and on the initiative of ALS Canada to take a leadership role.

President Michael Mayne and I travelled to Halifax in September to meet with the board of directors' of the ALS Society of Nova Scotia. This continued the program of meetings Michael and I began last fall when we traveled out west. The NS board members provided valuable feedback on the vision, the strategic plan and the partnership agreement amendment proposal. I then visited the new premises of ALS Québec in the company of board member Richard Thompson a week later to meet with Lise Deschesnes, president and Claudine Cook, executive director. We discussed the same issues as in Nova Scotia and identified methods of ensuring the quality of the French language version of our English materials.

Over the weekend of October 29 - 31 we held the Second Biennial Symposium in Toronto with more than 100 attendees. Friday evening led off with the screening of an National Film Board of Canada film on the life of a British Columbia man with ALS and his family. Saturday’s program consisted of two plenary sessions on caregiving, followed by research, while the afternoon consisted of workshops on fund development, advocacy, caregiving and dealing with grief.

In the evening we went to the Ontario Science Centre where we had a private viewing of the Gee! in Genome project, a highly interactive exhibit that explains the concept of genetics in lay terms.

Sunday’s sessions were on partnerships and then a two-person presentation on living with ALS, presented by Patricia Van Loan and William Weir, followed by a question and answer period.
On a Roll in BC

Rick Wilkinson, was diagnosed with ALS last year at the age of 42. Riding his power wheelchair, he left Campbell River on June 3rd and arrived in Victoria eight days later.

Wilkinson was supported by a team of 10 volunteers. En route to the capital, people with ALS joined this journey of hope. Many communities in BC hosted events in support of “On a Roll,” and as they passed through island towns and cities, Local residents, municipal, provincial and federal politicians came out to greet the team. Students at one school in Wilkinson’s home town of Duncan raised more than $400. On June 11th, Wilkinson rolled into Centennial Stadium at the University of Victoria where the Victoria International Track meet was underway. More than 3,000 people gave Wilkinson, his family and the “On a Roll” team a standing ovation as they rolled down the track and crossed the finish line - a powerful ending to an amazing journey.

His son Bryce - without his parents’ knowledge went door-to-door with a pledge sheet and raised $420 for his father’s cause.

Sharon Bardsley, an ALS Society of BC board member says, “I for one as well as the rest of the family (she is Rick’s sister) are very proud of him and it does give him a purpose which is so important when this disease takes so much of your world away from you.”

Caregivers - Take Care of Yourselves

About the author: Barbara Dickinson is the Director of Alumni Affairs at Brown University, a national trustee of The ALS Association and a former caregiver.

The patient is not the only victim of ALS. Sadly, the disease deeply affects caregivers, too, and even friends who are not on the front line. There is no disguising that caring for someone with a debilitating disease like ALS is taxing and exhausting. Caregivers need to understand that the emotions they experience are normal. They need to find ways to take care of themselves, even at the risk of feeling guilty or selfish.

During the ten years that our sons and I cared for my husband, I often felt angry, despairing, and guilty. I was not surprised to be in despair. I was deeply frightened and anxious, afraid for myself, my husband Brian and our sons. What was going to become of me? Could I carry on, would there be enough money, where would I find enough help? Were Brian and I, him through illness, me through neediness, irrevocably damaging our sons and limiting their futures?

I was often angry, as were we all. I was mad at a medical system that blithely said, “the family can take care of this,” whether it was replacing a G-tube (feeding tube) or adjusting ventilator settings or diagnosing incipient pneumonia. Brian was demeaned by his illness, and he was often impatient. Our sons were furious that their adult lives seemed to be on hold. And every day, the workload increased. I was always so tired.

And guilt-guilt was my name. How could I be angry or tired? I could walk and talk and eat and breathe on my own. I wasn’t dying. I had help and resources. So why couldn’t I do more, give more, be less selfish, be less impatient and less sick of sickness. Why did insignificant things trouble me? It was clear to me that I was not a good person, and yet any criticism destroyed me. My tombstone would read: “She did her best, but it wasn’t good enough.”

ALS took a lot away from us. First of all, despite our best efforts, Brian died. We inhabited a world of illness where crisis became the norm. We gave up our privacy, as more and more health care personnel joined us in caring for Brian. Our house became a hospital of sorts.

Continued on Pg 14
Our second biennial symposium was a great success. Attending the event were ALS board members, health-care professionals, people with ALS, current and former caregivers, ALS Society staff from across Canada, volunteers and family members.

The weekend started with a viewing of “Bearing Witness” a story of living with ALS, featuring Robert Coley-Donahue of BC, whose wife also had ALS.

Saturday morning commenced with a plenary session with Terry Wise, who was the primary caregiver for her young husband who had ALS. Wise was left a widow at the age of 35. Her plenary session was entitled “Rarely Heard Insights & Choices for Hope: A caregiver’s perspective.”

Her session was followed by Dr. Janice Robertson whose research group was recently established at the Centre for Research in Neurogenerative Diseases at the University of Toronto. Dr. Robertson discussed, “ALS research: from past to present and future directions.” Her work is supported by grants from the Motor Neuron Disease Association, (UK). The American ALS Association (US) and the Canadian Institutes of Health Research - Neuromuscular Research Partnership.

For the first time we hosted a number of exhibitors: Novartis Medical Nutrition; BHM Medical, Inc.; Zygo Rehabtek; Universal Motion and HME Ltd.; Qualife Canada Inc., and Shoppers Home Health Care. Also new this year were 11 poster presentations representing work done by our partners in BC, Manitoba, Ontario, PEI and New Brunswick and Alberta.

“The educational poster display exhibit is an avenue for our unit/society partners to celebrate their efforts and provides ideas for symposium participants to take home and use in their communities,” explains Jane McCarthy, director of services & education.

A series of workshops were held throughout Saturday on: Bearing Witness: Raising Awareness, Indulgence of Hope, Advocacy, Trends in Fundraising, The Masculine Face of Grief, Planned Giving and Care for the Caregiver.

Saturday evening culminated in a special private viewing of “The Geee! in Genome” exhibit at the Ontario Science Centre. This exhibit is an innovative project designed to inform Canadians about genomics - the study of genes and their functions. It is a national educational project produced by the Canadian Museum of Nature and presented nationally by Genome Canada in partnership with the Canadian Institutes of Health Research. During the evening participants had a chance to go on a deep journey inside the cell, discover their family tree and build their own DNA model.

The Sunday morning plenary session featured Sharon Baxter, executive director of the Canadian Hospice Palliative Care Association discussed the “Power of Partnership.”

At the closing session we heard from two powerful presenters who live with ALS, Patricia Van Loan from Ottawa and William Weir from Hamilton. They discussed “Living with ALS - the Journey.” Patricia Van Loan’s talk can be found on page 7.
Canadian Walk reaches the $1.6 million mark

In brilliant red walk t-shirts, 10,000 Canadians participated in 54 walks across the country in the fourth annual Walk. More than $1.6 million was raised nation-wide.

“The Walk raises substantial funds and builds awareness of this devastating disease. More than 1,000 volunteers and many staff are involved in making the Walk a resounding success. We are very grateful to our national sponsors McDonald's Restaurants of Canada and Canon Canada,” says Matthew Weisenfeld, development co-ordinator at ALS Society of Canada.

For the third consecutive year Canon Canada Inc. has come on as a national sponsor of the walk. “Canon is dedicated to provide ongoing support to the Walk, says Stan Skorayko, vice president of corporate communications for Canon Canada Inc. “We hope that the funds raised at this annual event will find a cure for the large number of Canadians who are affected by this tragic and debilitating disease.”

“McDonald's is thrilled to support the ALS Society across Canada,” explains Richard Ellis, vice president communications & public affairs, McDonald's Restaurants of Canada Limited. “I've seen first-hand the support people living with ALS and their families receive through their local ALS Society units and McDonald's is proud to support such a tremendous grassroots organization.”

Sixty per cent of the money raised remains with the communities for services such as equipment and home care, while 40 per cent goes directly to the ALS Society of Canada research fund.

The walks received prominent news coverage across the country from front page coverage in The London Free Press to a full page editorial in The Kingston Whig Standard. Local communities coast-to-coast covered the walks and people behind the walks.

Next year’s event promises to be even bigger and better. We will be rebranding the name and look of the walk for 2005. Check our web site at www.als.ca for our new look and name for the 2005 walk!

Walks took place in the following provinces/cities across Canada:

British Columbia (Okanagan, Prince George, Victoria, West Kootenays) $123,000
Alberta (Carstairs, Didsbury, Edmonton, Lloydminster, Medicine Hat, Cold Lake, Red Deer) $166,000
Saskatchewan (Regina) $31,000
Manitoba (Brandon, Dauphin, Winnipeg, Belmont, Thompson, Morden) $138,400
New Brunswick (Moncton, Fredericton, Miramichi) $35,000
Nova Scotia (Digby, Halifax, Inverness, Sydney, Truro) $94,529
Newfoundland (Brownsdale, Corner Brook, St. John’s, Stephenville, Wabush) $35,000
Prince Edward Island (Oyster Bay Bridge) $37,000
When I was called a few weeks ago and invited to speak at this symposium, I have to confess that my first, instinctive response was to say 'No, thank you!' Public speaking is about last on my list of things that I want to do. However, my more measured reaction was to accept because I have a great deal of respect and admiration for the mission and work of the ALS Society. I have certainly been a grateful recipient of their services and support, especially via ALS Ontario and particularly those from the local level through the tremendous work of the Champlain Regional Office. So, on that basis I am very happy to be here this morning albeit very nervous.

In her 1977 book “Illness as Metaphor” Susan Sontag wrote that when you become a patient you become a citizen of the night side of life you become a resident in the ‘kingdom of the sick.’ ALS places you squarely and irrevocably in the centre of this “Kingdom”!

In my previous life - as Sontag would describe it - in the ‘kingdom of the well’ I worked initially for several years as a Registered Nurse and subsequently for many more as a Social Worker. The majority of those years were either in palliative care or long term care areas. Not surprisingly, then, I thought I knew something about serious illness, loss and dying. And, of course, I did, in a professional sense and in a somewhat objective, detached and theoretical way. But now, because direct experience is, indeed, the best teacher, I believe that I know more. It is this experience, my residency in the ‘kingdom of the sick’ - my journey with ALS - that I want to talk about in the hope that this sharing will provide you with additional insight and understanding about living with ALS. For any of you who support people with ALS, above all I want to reinforce your conviction of the need to respect and protect the dignity and humanity of each patient and family.

To begin: in Nov. ’99 I was diagnosed with familial ALS. Like many ALS patients, the road to the definitive diagnosis was a long, arduous and, at times, frightening passage. Even with a significant family history of ALS my mother and her three sisters I had collected various diagnoses over several years, including fibromyalgia, chronic fatigue syndrome, arthritis, depression, and my particular favorite restless leg syndrome. By the time that I saw the neurologist that awful November, I was quite desperate and reasonably certain that I had ALS. Therefore, and paradoxically, having the neurologist confirm it was a relief: finally I could put a name to what was happening to me and know what I was dealing with. At the same time, of course, with his actual saying of those terrible initials ALS I was overcome with fear, dread and panic. For days it literally took my breath away. Being diagnosed with ALS, especially when you have full understanding of and intimate family experience with the disease is like waking up in the middle of your worst nightmare and discovering that it is reality. In ways I never could imagine, ALS laid me bare - physically, emotionally, psychologically and spiritually. You have heard the expression ‘going to the edge of the abyss.’ Well I actually felt as though I had fallen into the abyss: nothing felt solid; I felt that I was tumbling head over heels. It was a period of complete chaos and despair during which I questioned everything - my beliefs, my strengths, my weaknesses, and who I was as a person. I really didn’t know how I could live with ALS without going mad.

The early weeks and months following my diagnosis were a stark, solitary, intensely personal struggle and journey that gradually transformed me in the most profound and fundamental way. Perhaps what St. John would describe as ‘many dark nights of the soul.’ Only by going to the very core of your being can you literally start to reconstruct yourself and marshal your inner resources, to begin to deal with the reality and meaning of having ALS. Although it was a lonely journey it was made possible and supported by the unshakable love and presence of my family - especially of my husband, Nigel, by the heartening encouragement of a few close friends, and by the inspiration of my faith.

The answer at which I arrived, the only acceptable way for me to live with ALS, is complete acceptance and surrender. Let me explain: acceptance because I recognize that ALS is a part of me, in my case a genetic code laid down generations ago, something over which I have no control and for which there is, as yet, no cure; surrender, not in the sense of giving up hope - because I still have a great deal of hope - but surrender into God’s hands with an absolute conviction that He cares for me, that He is with me and that, ultimately, He knows what is best for me. Trying to find the right words or vocabulary to adequately describe what I mean by acceptance and surrender is difficult. However, I discovered that a wonderful American poet and writer, Philip Simmons, who also had ALS, had written an extraordinary book, “Learning to Fall: The blessings of an Imperfect Life,” in which he captured the essence of what it is I am trying to describe.

“...Only that we be in the presence, that we fully, consciously, hand ourselves over. That is all, and that is everything. We can participate in mystery only by letting go of solutions. This letting go is the first lesson of falling, and the hardest.”

Another book that I found to be very helpful during this early phase of my journey with ALS was Victor Frankl’s book, ‘Man’s Search for Meaning.” Throughout the time that I was working in healthcare, I had on my desk a quote from this book. Although I had always found it profound, I didn’t truly understand it until I was enmeshed in my own struggle to find some form of ‘peaceful coexistence’ with ALS.

“Everything can be taken from man but one thing: the last of the human freedoms-to choose one’s attitude in any given set of circumstances, to choose one’s own way.”

With that understanding I was able finally to make a very powerful and somewhat defiant decision: while acknowledging the power of this disease to destroy me physically I was determined not to let ALS touch my spirit or my soul.
The Gregor Effect is what happens socially to a terminally ill patient and their family who live in a society, such as ours, that to an extraordinary degree avoids serious illness, death and anything associated with it. Gregor is taken from Franz Kafka’s book, “The Metamorphosis,” in which the main character, Gregor, is transformed into a giant insect. In essence, the novel describes the reaction of Gregor’s family and friends to his ‘insecthood’ and the strategies, which they use to distance and separate themselves from him. In eventually seeing him as less than human and, therefore, less deserving, they are seen to closely approximate our society’s treatment of the terminally ill, giving name to the Gregor Effect. Like Gregor, those of us who have a terminal or chronic illness make the well uncomfortable: we confront society with mortality, a truth that many would avoid. To become a patient in our society, a citizen of the kingdom of the sick – particularly one with a terminal illness – is to go from accepted normality to a segregated or marginalized status of lesser value. We may no longer have leper colonies, but society still has the impulse to distance itself from the terminally ill and their families, albeit in more subtle and sophisticated ways. It is what the late author Carol Shields alluded to as an uncomfortable hushed silence when she walked into a roomful of people aware of her terminal cancer.

This Gregor Effect is the source of my and many other terminally ill peoples’ greatest fears: fear of abandonment; fear of loss of meaning and worth; and, fear that one will not be able to live out one’s last days with dignity. I have experienced the Gregor Effect and the very real vulnerability of being a patient in our society; so has my family.

Certainly, a few of my family and friends have distanced themselves from me, but I have discovered that the ‘best’ stay close. ALS also brings new people into your life - ALS fellow travelers, their families, ALS volunteers and staff-the ALS community; these are some of the best people I have ever met. And, although some people may not return your calls, the better ones do: (e.g., Dr. Mount, Dr. Brown, and Dr. Jean-Pierre Julien.)

Finally, for me, paradox has been one of the most surprising discoveries in my ALS journey: as deeply sad as this time is, nevertheless, it is also a profoundly rich period when life can be lived with more clarity, deeper faith, and greater appreciation and love than ever before.

In closing, let me borrow from Philip Simmons’ wonderful book once again because he captures and expresses this paradox so beautifully:

“...in falling we somehow gain what means most. In falling we are given back our lives even as we lose them.”

Patricia Van Loan delivered this moving speech at our second biennial symposium - Unmasking ALS, October 29-31. She spoke at the closing session, which was entitled “Living with ALS - the Journey.” Her husband Nigel is a member of the ALS Society of Canada board and president of the President of ALS Ontario.

Hike 4 ALS: Join us in Taking Steps to Find a Cure

Hike 4 ALS is a new national fundraising program targeting outdoor enthusiasts. This annual event is being run in Canada through a partnership between Hike 4 ALS and the ALS Society of Canada and supports ALS research and patient care services for those living with ALS and their families.

Matthew Wiesenfeld, development co-ordinator explains, “Hike 4 ALS is optimistic that our efforts will help researchers move faster to finding those new discoveries, making a difference for those living with the disease today as well as those who will be diagnosed in the future.”

Hike 4 ALS is comprised of two components. The first is a signature hike to an international destination to increase awareness of ALS, to raise funds, and to create market interest for our North American hikes held in the following months in communities throughout Canada and the US. In 2004, the signature hike was a 16-day trek to Mount Everest in Nepal and in 2005 the signature hike will be to Machu Picchu in Peru.

The second component is our North American hike series occurring on National Trails Day, in June, in the US and in September in Canada. These hikes are designed to offer something for hikers of all skill levels and are the easiest way for most people to participate in Hike 4 ALS. Participants pre-register on-line and all participants will be encouraged to solicit donations in addition to a modest registration fee. To make fundraising easy, each registered participant will be set up with a personal web-page with access to on-line fundraising tools.

Local hikes will be held in several North American cities in 2005. Canadian cities expected to host this event are Vancouver, Whistler, Calgary, Banff, Edmonton, Winnipeg, Toronto and Halifax. Additionally we have also developed an in-school and virtual hike program if these proposed locations are not convenient.

For more information contact: Matthew Wiesenfeld, mw@als.ca or 1-800-497-267-4257 x 202.
Reserve these dates

The ALS Association will be holding its annual Leadership Development and ALS Clinical Management Conference from March 10-12, 2005 at the Chase Park Plaza Hotel in St. Louis, Missouri.

The leadership track is for non-profit staff and volunteer leaders to further develop skills in building organizational capacity and public awareness of ALS. The clinical track is to help health-care professionals further their education of ALS through workshops, panel discussion and networking opportunities.

Please note this is not a patient/family conference. For more information email alsinfo@alsa-national.org

ALSA Canada will be holding its annual board meeting in the nation's capital April 29 - May 1st, at the Sheraton Ottawa hotel. The board meeting will be combined with a day of advocacy training and visits to MPs.

In late 2007 (November/December) the ALS Society of Canada will host the 18th International Symposium of ALS/MND in Toronto. This annual gathering brings together the top scientific and clinical minds in the world along with patients and caregivers to discuss the progress of research towards care and cure for ALS. Having the symposium in Canada will allow us to profile the superb work being done by the Canadian scientific community.

Something Important to Think About

Making a planned gift to the ALS Society is easier than you think! Not only are there several convenient options but your gift can be specifically designated for research, services, the ALS Society of Canada, or for one of the provincial ALS Society partners. It's completely up to you.

Your planned giving options include:

- Bequests - A donation of cash, property or other assets made through your will.
- Life Insurance - You can make the ASL Society the beneficiary of an existing policy or create a policy specifically for us.
- Gift Annuities - Can provide a tax free source of income to you while still making a gift to the ALS Society.
- Gifts of Residual Interest - You can establish a trust fund using cash, real estate or other assets. While you receive the income generated from the trust and the potential tax benefits, the ALS Society receives the principle upon your death or that of your named beneficiary.
- Publicly Listed Securities - Federal legislation has made the donation of stocks, bonds, mutual funds and other publicly traded securities to charitable organization a very attractive option.

If you would like further information on the ALS Society's planned giving program please contact Bob Appleton, director of development at 1-800-267-4ALS (4257) x 228 or ra@als.ca

The Health Improvement Institute has awarded the International Alliance of ALS/MND Associations website a Certificate of Merit in 2004 Aesculapious Awards.

ALS Society Staff Announcements

Joining the ALS Society of Canada team is Bobbi (Roberta) Greenberg as director of communications. Bobbi replaces Susan Graham Walker who has assumed the post of executive director of the ALS Society of Ontario. Susan replaces Karen Ormerod.

ALS Society of Ontario has a number of new staff. Helen Taylor, former co-ordinator of volunteer services has been promoted to regional manager - Greater Toronto Area. Helen replaces Charles Hain. Elena Pochapski joined ALS Ontario as finance manager. She replaces Nelly Teitelbaum.

The ALS Society of Québec has a new executive director - Claudine Cook and a new social worker Véronique Pignatelli. ALS Québec has also moved to new premises at 6300 Park Avenue, Suite 502, Montreal, PQ, H2V 4H8 and has a new web site address - www.sla-quebec.ca

The ALS Society of Alberta welcomes Wayne Steer as the Manager, Resource Development.
In March of this year the Toronto auditions were held to select three inspirational people to be torch bearers for the Montréal stop of the global Olympic Torch relay. The panel of Olympian judges was looking for individuals to help showcase the best in humanity and they found it in William Weir.

Weir’s success is a testament to his independence. He achieved a great honour by being selected as torch-bearer and shows that as a person with ALS he has the ability to accomplish great things. Weir was diagnosed with ALS in 2000, and is a former board member of the ALS Society of Toronto.

Weir stated in his award-winning speech what the Olympics mean to him, “I have always seen the Olympics as a very unique way in which the family of nations plays homage not just to the excellence of athletics, but also to some of the nobler characteristics found in the human spirit, while also revealing the very essence of human frailty.

“When I watch the games, I like to watch, close up the faces of the participants before and after the event. I look for the passion, spirit and focus and the desire to creatively express themselves to their full potential. We do not talk about the creativity in athletes like we do in music or art, but it’s all there. We see it, we feel it, we respond to it. We rarely talk about it.”

The month of November has been an award-winning month for Elizabeth Grandbois of Burlington, Ontario. Grandbois received one of 17 Ontario Outstanding Achievement Awards for Volunteerism in Ontario at a special ceremony in Hamilton on November 3, hosted by MPP Marie Bountrogianni, Minister of Citizenship and Immigration. This award - for individuals, groups or businesses for superlative contributions to the voluntary sector - recognizes and highlights the contributions of recipients and serves to inspire others by the positive examples they provide.

Grandbois received the award for the work she has done with a committee of talented, dedicated volunteers to stage the Concerts of Hope. She was recognized in her efforts “in raising a voice for ALS in her community where previously there was none.”

ALS is not a curable disease, but it is a treatable one. Treatments are now available that can make a major difference in prolonging life and enhancing the quality of life for people with the disease, and there are treatments for many of the symptoms of ALS that can help ease its burden. Although the diagnosis of ALS can initially be devastating, the vast majority of people discover new courage from within to battle this disease and live life with vigor and enthusiasm. The information in this book will prove useful to people with ALS and their families both in managing the disease and living within its limitations. The cost of the book is $22.95 US Funds. For more information contact Demos Medical Publishing, 386 Park Avenue South, New York, NY 10016 www.demosmedpub.com
Updated Manual for People Living With ALS

The third edition of the Updated Manual for People Living with ALS is an excellent educational resource and tool. It will help readers to organize personal health information and stimulate discussion between patients, family members, and their health-care providers about managing ALS care and coping with an often rapidly progressive neurological condition. The manual will be available in early 2005.

Director of services and education Jane McCarthy says, “This is a comprehensive resource that reflects input from a wide variety of ALS professionals across Canada. The review committee included three neurologists, a physiatrist, two people with ALS and current and former caregivers.

“The manual is formatted in a binder with coated tabs for quick reference, and also includes tools, charts and highlighted lists to make it easier to review the large amount of information contained in the publication. We are confident that the manual will be perceived as a valuable resource, especially for those recently diagnosed with ALS.”

Who should have a copy of the Manual?
• Persons living with ALS, especially those recently diagnosed
• Family and other unpaid caregivers
• Health-care providers with patient(s)/client(s) with ALS
• Long-term care organizations (homecare and in-patient facilities)
• Palliative and hospice-care organizations
• Hospital and public libraries

How can I get a copy of the Manual?
• For individuals with ALS, family caregivers, or health-care professionals with patients/clients with ALS, please contact your local provincial ALS Society
• Other interested health-care professionals/organizations, please call 1-800-267-4257, or in the Toronto Area 416-497-2267
• For PDF print-only version, download from our web site - www.als.ca

How much does the Manual cost?
• $20 for libraries, schools, health-care facilities and other organizations, not currently involved in ALS care

Bearing Witness

This film follows Robert Coley-Donohue over the last three years of his life. A retired machinist, he is determined to make the most of his time. He lives independently for as long as possible. In his typically understated way, he says, “This slow deterioration is not fun. Not fun at all.” With the help of homecare workers, Victoria Hospice and his three devoted children, Coley-Donohue remains at home. But the idea of staying and dying at home soon runs up against harsh realities. His 24-hour care is expensive and eventually, Coley-Donohue decides to move to a hospital where he spends the last nine months of his life.

Coley-Donohue’s experience is arduous, but also filled with hope and healing.

Director: Dan Curtis
Producers: Adam Symansky, Sally Bochner and Pierre Lapointe
Writer: Jim Osborne

VHS format
Price: $19.95 individuals; $49.95 institutions
Duration: 90 minutes

To order contact the NFB at 1-800-267-7710

Phil Simmons, associate professor of English at Lake Forest College in Illinois was diagnosed with ALS when he was 35. Simmons celebrates the wonder of life even as he is slowly dying of this disease. As his muscles deteriorate and his body becomes increasingly paralyzed, Simmons continues to ‘wrestle joy from heartbreak’ at each stage of his ongoing losses.

“At one time or another, each of us confronts an experience so powerful, bewildering, joyous, or terrifying, that all our efforts to see it as a problem are futile. Each of us is brought to the cliff’s edge. At such moments we can either back away in bitterness or confusion, or leap forward into mystery,” says Simmons, in his book “Learning to Fall,” published by Bantam Dell.

Duration: 77 minutes
Price: Video $30, shipping and taxes are extra

To order contact:
Beitel/Lazar Productions Inc.
2218 Old Orchard, Montréal, PQ
H4A 3A8
Phone 514-487-4562
Fax: 514-487-9729
Beitel_Lazar@videotron.ca
Kudos to award winners

A t the ALS Society of Canada annual meeting last April, we recognized the following individuals and provincial societies for their outstanding contributions to the ALS Society.

Joyce Sinclair, long-time ALS Society volunteer has been recognized for her support and service by being made an Honorary Life Member of the ALS Society of Canada. Honorary Life Members are named in recognition of an extraordinary volunteer contribution to the ALS Society of Canada. Up to three people may be named in any given year. Consideration may be given to former ALS Society of Canada and provincial society staff.

Sinclair has been actively involved with the ALS Society of Manitoba for more than 20 years. Her dedication and commitment to the society has been outstanding, especially through her strong leadership skills. She has represented the ALS Society of Manitoba on the ALS Society of Canada Board for the last three years.

“She engaged the Manitoba board in learning more about the benefits of partnership between the organizations. No task has been too big for Joyce. She has helped with the Walk, support groups, board activities, fundraising in general and has been a great proponent for public awareness” says Diana Rasmussen, executive director of the ALS Society of Manitoba.

Marie Salamoun-Dunne has been recognized for her support and service by being made an Honorary Life Member of the ALS Society of Canada.

In 1989, Salamoun-Dunne began her volunteer career with the ALS of PEI. Over the past 15 years she has become a highly recognized ALS voice and an active ALS advocate in Prince Edward Island and beyond.

Her primary contribution has been dedicated service to individuals diagnosed and living with ALS and their families in teaching, supporting and advocating in any way she can. In recent years she has responded to many and varied requests to present the personal side of living with ALS. The groups vary considerably from student nurses to professionals in the community and volunteers who require training to work with families and people with ALS.

Salamoun-Dunne has also made numerous presentations on bereavement and palliative care to professional organizations.

Gilles LeBlanc, president of the ALS Society of New Brunswick has been honoured by the ALS Society of Canada for his leadership with the ALS Society of New Brunswick. LeBlanc was awarded the William Fraser Leadership Development Award.

This award is given annually in recognition of outstanding leadership development - initiated and implemented - by an individual, chapter or unit. It may be awarded to a staff person or volunteer, or to individuals working in collaboration to develop the organization at a local, regional, provincial or national level. The award honours William Fraser, a past president of the ALS Society of Canada who died in 2000. Fraser valued leadership and organizational development highly, and exemplified both in his contributions to our organization. This award is open only to volunteers.

LeBlanc was diagnosed with ALS in 1999. Maloney was integral in bringing BC its first Walk. In 2002, he became the family team chair of the West Kootenay Walk. His leadership as team chair along with the efforts of the rest of the walk committee resulted in more than $45,000 being raised. As the top fundraiser of this walk his team raised approximately $10,000.

He strongly encouraged the Victoria Chapter to hold a Walk by sharing his positive experience of the West Kootenay Walk. Through his encouragement and with his willingness to be the family team chair, a Victoria walk committee was struck. Maloney worked hard to recruit family teams as well as set up his own team up and running. He was integral in garnering support from local businesses especially his former employer, Island Farms Dairy. The Victoria Walk raised more than $47,000. Once again, he was the top fundraiser, with his team raising an incredible $20,000. Maloney is a wonderful example of how a person with ALS can make a significant difference in the lives of others and have a legacy that will continue far beyond his own personal involvement.

It is with regret that we announce that Dan Maloney passed away in September 2004.

George Goodwin of Hamilton Ontario is the recipient of the ALS Society of Canada Exceptional Public Awareness Award. This award recognizes an exceptional program that aims to educate and increase public awareness of ALS. Public awareness activities may include liaisons with the media, co-ordinating public awareness displays, speaking to the public or other organizations about ALS. There are two categories of eligibility 1) individual and 2) a group of two or more people.

Goodwin, who lives with ALS, has worked tirelessly to raise awareness of this devastating disease. He brought the powerful March of Faces program to Canada, and has since then managed and marketing the project nation wide. The March of Faces banners are extremely effective awareness tools when displayed at fundraisers and other events. Goodwin has pursued this task with considerable diligence and perseverance - to the point where almost every province in Canada has at least one March of Faces banner. These banners have proven to be an extremely effective awareness tool when displayed at fundraisers and other events.

Contd on Pg 13
Kudos to award winners

Continued from Pg 12

**Calgary’s Betty Run for ALS** was awarded the ALS Society of Canada Exceptional Fundraising Program Award. This award recognizes excellence in a fundraising program implemented during the past year and is given to an individual or project team who have developed an innovative idea and attains or exceeds a fundraising goal. It can be a new or continuing program. There are two categories of eligibility 1) individual and 2) a group of two or more people.

Kelly Eaton, daughter of Betty Norman and Jane Rivest, of the ALS Society of Alberta accepted the award on behalf of the run committee.

In August 1996, Betty Norman, a vivacious, fun-loving, and very caring lady was diagnosed with ALS. Norman, her family and friends were frustrated by the lack of awareness about ALS and the small amount of research being funded at that time. In June 1997, just two weeks before she passed away, the first walk/run in Betty Norman’s honour was held in Calgary to raise money for ALS and to help increase awareness.

By June 2003, Betty’s Run for ALS achieved an extraordinary milestone by raising more than $1,000,000 in its seven-year history. To date half of the net proceeds of this event have been forwarded to the ALS Society of Canada research fund. The remaining funds have remained in Alberta to help provide appropriate equipment and support for people living with ALS.

Betty’s Run for ALS has also been the leading force behind two sets of the public service announcements for ALS, thanks in great part to the participation of award-winning Canadian actress Wendy Crewson in 1999 and 2003.

**Audrey and Duncan McKinnon** of Newmarket were awarded the Brett Yerex Exceptional Advocacy Award by the ALS Society of Canada. 2003 marks the first time that this award was offered. The Brett Yerex Exceptional Advocacy Award recognizes an exceptional advocacy initiative that seeks to improve the quality of life of a person or persons with ALS during 2003. In January of this year the ALS Society of Canada named this award to honour the work and commitment of Brett Yerex who died in January 2004. There are two categories of eligibility 1) individual and 2) a group of two or more people.

Audrey and Duncan McKinnon have, individually and as a couple, shared their experiences and trials of living with ALS to help shape public policy that affects many Canadians, not just those with ALS.

They have constantly opened their home to journalists, photographers and TV crews to film Duncan, who lives with ALS, in his lift or showing the challenges of accomplishing simple routine tasks.

Indeed Audrey McKinnon’s eloquent presentation to the parliamentary standing committee on finance helped to bring about the first federal compassionate leave and income security program. The ALS Society of Canada is grateful to these advocates who have utilized their own situation and their own pain and exhaustion to energize and motivate others to action.

It is with regret that we announce the death of Duncan McKinnon this past June.

Ruth McFeat of Dutton was awarded the Myra Rosenfeld Volunteer Award by the ALS Society of Canada, for her longstanding and invaluable contributions to the London Chapter as well as her important governance work.

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

Ruth McFeat became involved when her husband Forest was diagnosed with ALS in 1996 and since then she has tried to assist others with their journey. Currently, McFeat holds four different volunteer positions with the ALS Society of Ontario. She is the president of the London Chapter, the co-ordinator for the London caregiver group, a member of the provincial advisory council and board of directors of the ALS Society of Ontario.

Most recently, McFeat was a member of the Ontario governance committee charged with the task of downsizing the board and regionalizing the provincial society.

**Award eligibility**

1. The nominee(s) must be a volunteer(s) or staff member (unless otherwise specified) with the ALS Society of Canada or provincial society.

2. Individual award nominees must be volunteers and group-award nominees may include staff.

3. The award may be awarded posthumously, provided the person was involved with the society in the past year.

4. The award will be presented at a special ceremony at the annual meeting of the ALS Society of Canada, April 30, 2005.

Any award may or may not be made in a given year.

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**March 31 deadline**

It’s not too early to be thinking about who you would like to nominate for the 2004 awards. March 31, 2005, is the deadline for the ALS Society of Canada’s awards program. Please think about those special people who have given their time and effort to promote the ALS cause locally, provincially or nationally. The awards committee has made some modifications for the awards criteria for the 2004 awards - nomination forms can be downloaded from our web site at www.als.ca. For more information, please contact Enzo Raponi at er@als.ca, 1-800-267-4257 ext. 205.
Caregivers - Take Care of Yourselves

Continued from Pg 14

We are not healed completely from our experiences, physically or emotionally, and perhaps we will always carry with us the effects of ten years of stress and grief.

But, ALS leaves legacies that are unexpected. We each learned what we were, good and bad, and we learned to be tolerant of each other's failings. We gained perspective. We learned to value the small pleasures of life and to laugh at its general absurdity as well.

We are now stronger, more generous, more patient as a result of our experiences. We are a tight family, understanding and supportive of one another.

After all, we did cope. Our sons finished their educations, got jobs, and got married during Brian's illness. Two grandchildren were born. I continued to work. We gave holiday parties, we visited with friends, we went on excursions.

We tried for normalcy. We had time to talk and to reflect. We learned to negotiate, to manage, to co-operate. We know that we helped Brian live a productive and comfortable life with ALS; we did all we were capable of, and we are proud of that. And we are pretty sure that we can now handle just about anything that life throws at us.

What helped each of us the most was stepping out of the situation whenever possible. Caregivers often feel guilty about taking any “R & R” for themselves, but they must. The most important advice I received when my husband was first diagnosed was, “A lot of people will be taking care of Brian, and no one will be taking care of you. You must find ways to be good to yourself.” Caregivers, take care of yourselves. Accept all the help you can get. Schedule yourself free time. You will be better off, and so will the patient. And forgive yourself. You are doing the best you can in the hardest job you’ll ever have.

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ALS. Three letters that change peoples lives. FOREVER.
Two Studentships Granted

David S. Cameron, national executive director of the ALS Society of Canada is pleased to announce that the ALS Society has created a new program to fund young researchers as they embark on their careers in ALS research.

“This is a new program. We have awarded two recurring annual grants of $20,000 per year (for up to three years) to ensure that the scientific community in ALS will be populated in the coming years.

We believe that there is a real need to seed the future of ALS research by encouraging young scientists to get involved in the field. We will continue to provide incentives and assistance to these future members of the ALS research community in the years to come.”

The ALS Society partnered with the Canadian Institutes of Health Research (CIHR) for the studentships. CIHR reviewed the students’ applications for scientific merit and excellence and the ALS Society of Canada provides the funding for the studentships.

Miranda Tradewell’s research project “The Role of Calcium in Motor Neuron Disease” will be funded for three-years. Tradewell is currently pursuing a PhD in Neuroscience. The goal of her research is to understand why the normal biology of motor neurons makes them vulnerable to the toxicity of these mutant proteins compared to other cells. Information gathered during the course of her experiments may also be important in other neurodegenerative processes, such as Parkinson’s or Alzheimer’s diseases, as similar events leading to neuronal death may occur.

Edor Kabashi’s research project “Problems with Protein Disposal in ALS,” will be funded for two years. The main goals of his research are to contribute to a better understanding of the pathophysiology of ALS and other neurodegenerative disorders and to offer new therapeutical agents to help people with this devastating disease. He will study the mechanisms of toxicity and vulnerability of motor neurons in models of a familial form of motor neuron disease. Kabashi is pursuing a PhD in Neuroscience.

The students will be working under the direction of Dr. Heather Durham at the Montréal Neurological Institute, McGill University. Durham’s research has focused on understanding how the physiology of motor neurons increases their vulnerability to stresses associated with diseases. The Durham laboratory has developed a unique culture model of familial ALS and is one of the few laboratories in the world that examines primary motor neuron cultures, providing a unique opportunity to examine motor neurons in vitro. “The overall goal is to understand why motor neurons are so vulnerable to damage in ALS and other motor neuron diseases,” explains Durham.

Elizabeth’s Concert of Hope - February 12, 2005

Tickets are now on sale for the fifth Elizabeth’s Concert of Hope and are available from the Dofasco Centre for the Arts in Hamilton - 1800-456-PLAY. Elizabeth’s Concert of Hope is an established annual musical extravaganza, which has raised more than $1.3 million in research. “Music will always be with us. It is a universal language that carries the message of joy, humanity and hope from the past, through the present, and into the future,” says Elizabeth Grandbois.

The following is a list of committed and caring entertainers who have shared their talent:

Amy Sky
La Bottine Souriante
Natalie MacMaster
Cindy Church
Loreena McKennitt
Quagmire
Dan Hill
Marc Jordan
Quartetto Gelato
David Broadfoot
Michael Burgess
Susan Aglukark
Hang Time Circus
Michel Rivard
The Nylons
Ian Thomas
Michelle Wright
The Good Brothers
Jean Stilwell
Murray Mclauchlan
Tom Cochrane
Jesse Cook
Nanette Workman
Wendy Crewson

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

For more information about Elizabeth’s Concert of Hope go to http://www.elizabethconcertofhope.com
ALS Society of Canada Staff

ALS SOCIETY OF CANADA STAFF
Left to right - back row - Matthew Wiesenfeld, Robert (Bob) Appleton, Jane McCarthy, David Cameron and Enzo Raponi.
Front row - Karen Hunter, Darija Ilic, Indra Patterson, Bobbi Greenberg and Claudia Daniel.

Contact ALS • 1-800-267-4257

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