

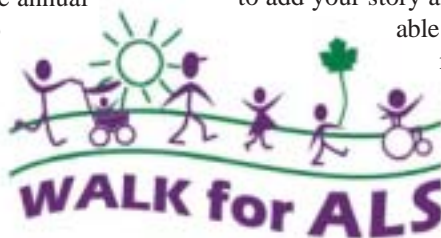
# ONTARIO JOURNALS



Spring 2005

## Walk For ALS - A New Look for 2005

In January the ALS Society of Canada unveiled a new look for the annual walk. The Society is also pleased to announce a new fundraising vehicle for the walk - the ONLINE FAMILY PAGES. The Online Family Pages will enhance your ability to raise money to support care and cure for ALS.



These personal web pages will allow you to add your story and photos and then enable you to connect with donors and friends online.

Visit our website at [www.alsont.ca](http://www.alsont.ca) to stay up to date with the official launch of the online family fundraising pages and online receipting.

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### Spring Walks 2005

| City               | Date    | Location                           |
|--------------------|---------|------------------------------------|
| Cobourg            | May 1   | Victoria Park                      |
| Alliston           | June 4  | Alliston Christian Reformed Church |
| Mississauga        | June 11 | Erindale Park                      |
| Kitchener/Waterloo | June 12 | Waterloo Park                      |
| Brantford          | May 29  | Fordview Park                      |
| Durham             | June 4  | Rotary Park                        |
| Peterborough       | May 28  | Nicholls Oval Park                 |
| Simcoe             | June 11 | Memorial Park                      |
| Toronto            | June 5  | E.T. Seton Park                    |
| Sault Ste. Marie   | June 26 | Bondar Pavillion                   |

For additional information visit the community pages section of [www.alsont.ca](http://www.alsont.ca)

## President's Corner

To most people it is a given that an organization cannot really grow and progress adequately and to good effect unless it has some idea of where it wants to go, some goals or objectives at least, but a fully developed plan is even better.



**Nigel  
VAN LOAN**

About three years ago, the ALS Society of Ontario developed just such a plan. In fact, we developed two: the Board of Directors, ably assisted by some key staff and representative people with ALS and

caregivers, structured an overarching Strategic Plan that set out goals and high-level objectives. The Society's staff, led by the Executive Director, then turned this strategy into an Operational Plan with concrete, specific objectives and resource allocations necessary to reach the objectives. The Board was thereby able to track the progress made against the Plan.

Well, it all worked! Or, at least, we did make considerable progress towards the goals we had set and were able to measure that we were making headway. However, for

see **PRESIDENT** page 3

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*The Ontario Journals is a vehicle for keeping you informed about the latest news with respect to ALS and the ALS Society of Ontario.*

# ADVOCACY & AWARENESS

## Numbers & Narrative

The ALS story is a powerful one.

### Powerful if told by numbers:

- Two to three Canadians a day die of ALS.
- There are 731 people in Ontario registered with the ALS Society of Ontario.



**Susan  
GRAHAM  
WALKER**

- 14% of the newly diagnosed are below 51 years of age.
- 35% are below 61 years of age.
- 232 newly diagnosed individuals registered with the ALS Society of Ontario in 2004.
- Over 150 people in Ontario died of ALS in 2004.

- The ALS Society of Ontario has an inventory of over 1,600 pieces of equipment with a total replacement value of \$2.7million.
- Equipment requests are filled within 2 weeks of receiving the information.

### Powerful if told by a narrative:

“ALS changes your life forever. I now have a permanent power wheelchair and we have made other adjustments such as renovations to our van and we have put in a wheelchair accessible ramp at the back of our house. We have also renovated our bathroom and added a ceiling track from the

bedroom to the bathroom. These renovations and my equipment are extremely expensive, but thankfully the ALS Society of Ontario helped us cover some of these costs.

Since my diagnosis six years ago we've had time to prepare ourselves for what is to come, being realistic, while always hoping for a cure. Our children have been told the truth over the years about what is happening to their mom and we have had professional counselling to help them understand what is going on around them.

ALS is a very costly disease, both physically, emotionally and of course financially. There have been many tears and a lot of frustration and anger. But so far we've managed. I am determined to keep going because my children need their mom and my husband needs his wife.”

As told in our recent mailing to donors.

In our advocacy program we use numbers and narratives to persuade elected officials, public servants and service providers.

Recently we have been using both numbers and narrative about home care to influence changes to Community Care Access Centres and to provincial policy concerning home care expenditures.

Three volunteers recently visited Elinor Caplan, charged by the provincial government to look into how CCACs award home

care contracts. William Weir, who lives with ALS in Dundas and his wife Jennifer, along with Advocacy committee chair Teresa Rivero, whose husband Ted died of ALS and myself spent a very productive 90 minutes with Ms. Caplan. We left promising to provide more information about the experience of CCACs from the ALS community. We set up an online survey and collected numbers and narrative from 40 people who presently access home care services. This, along with a thoughtful paper by William Weir on his specific situation, were delivered to Ms Caplan. Her report will be tabled in the coming weeks. We will keep you informed through our website.

A second opportunity was orchestrated by Jim Evans, a member of the ALS team whose wife died of ALS in 2003 and who has excellent contacts within government circles. Here again we shared numbers and narrative with two key policy advisors in George Smitherman's staff with responsibility for the home care file.

The Advocacy Committee is working to turn these opportunities into requests for specific action by the provincial government. Then we will mobilize our volunteer resources to hold a second DAY IN THE PARK later in the year. The numbers and narrative stories will then be brought to individual MPPs by those directly affected by ALS, asking for concrete action.

And then the cycle will begin again.

## Marketing/Communications Committee

The role of the Marketing/Communications Committee is to support the mission of the ALS Society of Ontario through the establishment and maintenance of a consistent identity to internal and external audiences.

Members of this new committee are Julian Franklin, Kristi Stewart, George Treheles, Nigel Van Loan and Tamara Walsh. Each brings with them expertise in the area of marketing, media, promotions and website

management. This mix of experience and dedication to ALS will ably assist them in achieving the following objectives:

- Set strategic direction for marketing activities to defined target markets based on the strategic plan of the Board of Directors.
- Assist fundraising and events committees in developing strategies and opportunities that will enhance their activities.

- Determine appropriate communication vehicles and themes.
- Identify and develop policies and procedures that best support the marketing objectives.
- Proactively identify and develop appropriate public relations opportunities.

# ADVOCACY & AWARENESS

## ALS Society Ad Campaign Asks: “What would you do, if you still could?”

The ALS Society of Canada is launching a new public service advertising campaign created by BBDO Canada to raise awareness about ALS and the ALS Society’s efforts to support research towards a cure for the disease.

The nature and progression of ALS lead many of those living with the disease to consider how they will use the time they have left. This campaign asks consumers to consider a similar scenario with the question — What would you do, if you still could?

Created by BBDO Canada on a pro bono basis, the campaign includes two, 30-second television public service announcements (PSAs): “*Running*” and “*Hugging*”. Sixty-seconds for cinema will be available later this year along with print and interior transits based on the same theme.

“We wanted to help people understand how ALS changes the lives of people living with the disease and those around them,” said Stephanie Nerlich, Senior Vice President, Group Account Director, BBDO Canada. “That led us to think about simple tasks that we take for granted, tasks that people living with ALS are forced to consider every day.”

BBDO Canada is responsible for managing the communication needs of some of Canada’s largest and best known brands. BBDO Canada, established in 1992, is a subsidiary of BBDO Worldwide, in turn owned by Omnicom.

Visit the ALS Canada website at [www.als.ca](http://www.als.ca) to view the ads, which are available in French and English.

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### PRESIDENT continued from page 1

some time now concerns have been growing that we needed to revisit and extend the Plans, to refresh our goals, reset the clock and assure ourselves that we were on the right track — or, perhaps, where necessary change tracks. So, late last month we gathered in Toronto for a full day of examining the vision, mission, goals and objectives of the ALS Society of Ontario. Similar to the previous venture, what emerged is a Plan that covers a swath from easily-achieved, sometimes self-evident objectives to very ambitious, potentially expensive and complex goals. In brief, five strategic goals were identified that define the most crucial priorities for the next three years.

#### Service for All

The ALS Society of Ontario will ensure that clients and families throughout Ontario are granted equitable access to programs and services that meet their diverse needs throughout the progression of the disease and beyond. This needs to be achieved through efficient and cost effective management.

#### Successful Fund Development Program

The ALS Society of Ontario requires an actively managed, balanced and growing revenue base that will allow the organization to execute its strategic plan.

#### Increased Awareness

The ALS Society of Ontario will increase awareness through consistent and appropriate message and image campaigns using a positive message appropriate for the targeted audiences.

#### Effective Advocacy

The ALS Society of Ontario will capitalize on regional opportunities to influence public policy to better serve those with ALS and their families.

### Vibrant Volunteer Base

The ALS Society of Ontario must support and be supported by an engaged, well-managed, and effective volunteer base across the province.

Your Board has directed the Executive Director to prepare a Plan for implementation of operations based upon this Strategic Plan. We will soon receive a proposed version of that Operations Plan and will review it at our next Board meeting. The Board of Directors will remain responsible for monitoring the Strategic Plan, and the budget needs will be approved by the Board of Directors within the bounds of fiscal responsibility.

I hope that this doesn’t sound like a lot of ‘managementese’, but the people with ALS and their caregivers deserve the best in support, and the best comes from a mature, well-managed and forward thinking Society.



Members of the Board review  
Strategic Planning Points

# LEADERSHIP & RESOURCE DEVELOPMENT

## ALS Ontario Volunteer Awards 2005

Each year the Society honours individuals who have made significant contributions to the ALS community and to the ALS Society of Ontario. The Esmond Butler and the Jack Muirhead Awards are presented at the Society's Annual General Meeting each year. Nominations for the awards may be made by any person and will be received for consideration by a Selection Committee.

Accompanying guidelines will direct those wishing to submit nominations which must be received by May 31, 2005.

Following are the criteria for each award.

### Esmond Butler Award

Esmond Butler was the private secretary to five Canadian Governors General. He provided stability by staying in a position that he could easily have used to move him on to a more powerful role. But, he believed in the institution he served and chose to remain in his position to provide consistency and to encourage change to this institution by endorsing sensible reforms. He died in 1989 after his battle with ALS.

The nominees for this award must have demonstrated attributes which reflect those of Esmond Butler: leadership; constancy; loyalty; and a positive stable impact on the ALS community through an extended time of volunteer service with the Society.

### Jack Muirhead Award

Jack Muirhead, himself a person with ALS for twenty years, was a "builder", a man "in the trenches". In 1988, Jack was instrumental, along with others, in bringing together a number of smaller ALS chapters to establish the ALS Society of Ontario. He then went on to serve as the Society's first President where he encouraged staff

and volunteers in their chosen roles and validated the importance of what each person did.

The recipient of this award should demonstrate the innovation, creativity, perseverance, thoroughness, and visionary abilities of this man who also showed great concern and care for people with ALS and their families.

### What You Need To Know

- Nominations being accepted for Esmond Butler and Jack Muirhead Awards
- Deadline for nominations is May 31, 2005
- Nomination Forms can be downloaded from [www.alsont.ca](http://www.alsont.ca)
- Awards to be presented at AGM

Nomination Packages, which are available on the Society's website, must include:

- Nomination form
- Two supporting letters written by individuals who have knowledge of the nominee and his/her contribution to the ALS cause.
- A 200 to 500 biographical sketch. Although it may include achievements and contributions dating back five years, emphasis should be placed on the previous year's achievements.

### Additional Information

- Equal consideration will be given to the areas of fundraising, public awareness and support services.
- Posthumous nominations are allowed.
- Current members of the Board of Directors are not eligible to receive the awards.
- Nominees must be residents of Ontario.
- The award will be presented at the Annual General Meeting in Toronto, the date to be determined. Please watch our website for further details.
- Questions and nominations can be directed to Suzanne McDonald, Director of Resource Development at 1-800-267-4257 ext 217 or [dirresdev@alsont.ca](mailto:dirresdev@alsont.ca).

## Elizabeth's Concert of Hope 2005

The fifth annual *Elizabeth's Concert of Hope* was held on February 12, 2005 at the Dofasco Centre for the Arts in Hamilton, Ontario. The theatre was packed for another exciting program that raises funds for research and support services for those living with ALS. It is anticipated that the concert will raise \$300,000.

A very special thank you to the artists who created a warm and fun evening. Pictured here is the group "Lunch at Allen's". These artists have been the backbone of this concert every year. In addition this

year's concert featured Johnny Reid, the Ennis Sisters, John McDermott, Hangtime Circus, Jason Belleville and Tom Cochrane.



The Group - Lunch at Allen's

To the volunteers on the concert committee we would like to express our heartfelt appreciation for you unwavering passion and dedication. The committee includes: Ted Bailey; Phyllis Bendig; Kathy Chittley-Young; Sue Dodds; Cheryl Eidt; Gary Ewart; Rosella Elgar; Elizabeth Grandbois; Kevin Hicks; Kathy MacFarlane; Glen Mcleod; Connie Smith; Heather Wray.

# SUPPORT SERVICES

## The ALS Society of Ontario's Equipment Program: Serving the Equipment Needs of People with ALS

To assist individuals diagnosed with ALS to cope with the daily challenges of decreasing mobility, communication ability and retaining independence, the ALS Society of Ontario set up the Equipment Program. At the end of 2004 the Society had 731 registered clients.

The program provides access to basic and essential assistive equipment in three ways:

- Loan of equipment.
- Purchase assistance for new equipment.
- Funding assistance for lease of communication devices.

The ALS Society of Ontario has a designated equipment list. Individuals requiring equipment not included in our list can put in a special request, which will be considered on the basis of resource availability.

### Program Eligibility

To be eligible for this program an applicant must:

- Have been diagnosed with ALS,
- Be registered with the ALS Society of Ontario, and
- Have accessed all other sources of financial assistance including private insurance, the Assistive Devices Program (ADP) as well as other government and non-government programs.

### Program Requirements

- All equipment requests should be prescribed by a qualified health professional using the Society's Equipment Application. To obtain a copy of this form go to [www.alsont.ca](http://www.alsont.ca) (under **our services**) or contact our Chris Forty Client Services Coordinator at 1-800-267-4257, ext 211.
- Individuals requesting funding for purchase or lease of equipment should obtain prior authorization from the ALS Society of Ontario.

### Program Limitations

- Equipment purchase, rental and lease assistance are available on a cost-sharing basis where up to 65% of the cost is paid by the Society and the remaining 35% is paid by the applicant. In extenuating circumstances, the Society may be able to waive or reduce the applicant portion of the funding.
- Since there are other programs in the community, the Society does not pay for home or vehicle modifications, assessment costs, home care services, or medications.
- Purchase requests for items costing less than \$100 will not normally be entertained although such equipment may be loaned out, if available.

### Designated Equipment List

We have many types of equipment that may be available for loan, lease/rental or purchase assistance. The following are indicative only and funding is not necessarily restricted to those items.

- *Bathroom Aids* (Shower commodes, transfer benches, bath lifts)
- *Mobility Devices* (Walkers, scooters, manual and power driven wheelchairs)
- *Lifts* (Transfer systems like floor to ceiling poles, patient transfer lifts and ceiling track systems)
- *Medical Equipment* (Suction machines, feeding pumps and basic respiratory equipment)
- *Miscellaneous Equipment* (Lift chairs, hospital beds, pressure relief systems and portable ramps)
- *Communication Devices* (Most types of communication and environmental control devices are available on lease through the Assistive Devices Program (ADP).

### Additional Information

For further information, please contact your local Chapter/Regional office, or Chris Forty at the ALS Society at 1-800-267-4257, extension 211.

## Facts & Figures

### Preliminary Survey Results

In 2003-2004 the ALS Society of Ontario conducted a survey of clients who use the Equipment Program. In addition to finding out how we are doing, the information we obtained was helpful to the board in the development of a new strategic plan and it will assist staff in preparing the operational plan for the next three years.

- 61% of our clients are younger than 61 and 14% are younger than 51.
- 64% of the respondents were male.
- 63% live in a house and 6% are in a long term care facility

- 46% have an annual family income below \$30,000 while 17% exceeded \$60,000.
- 84% of respondents were aware of our equipment program.
- 83% found the program useful.
- 83% found the used equipment loaned to them to be of good quality.
- 36% have used the program at least 3 times.

### Facts and Figures About the ALS Equipment Program

- We have 1,615 pieces of equipment in our inventory, housed in 14 locations throughout Ontario.

- Half of this inventory is in Hamilton and Toronto.
- Replacement cost for our most expensive equipment is \$2,700,000.
- In 2004 new purchases to our inventory totalled \$166,000 and donations were valued at \$200,000.
- We had 1,015 requests for equipment in 2004.
- 998 of the requests were filled with the other 17 being withdrawn.
- 75% of these requests were filled from our existing inventory.
- 83% of requests were completed within 2 weeks, and 61% of within 1 week.

# YES, I WANT TO HELP PROVIDE SUPPORT FOR PEOPLE WITH ALS!

Please accept my gift of:  \$25  \$50  \$75  \$100  \$250  other \_\_\_\_\_

Please find enclosed my cheque payable to the ALS Society of Ontario

I prefer to charge my gift to my credit card:  VISA  MasterCard  American Express

Card #: \_\_\_\_\_ Expiry Date: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Address: \_\_\_\_\_

City/Town: \_\_\_\_\_ Prov: \_\_\_\_\_ Postal Code: \_\_\_\_\_

Phone: (day) \_\_\_\_\_ (eve) \_\_\_\_\_

I want to find out how I can offer my time to help the ALS Society of Ontario and its people with ALS. I would like more information about:

Monthly Giving  Special Events  Volunteering  Membership \$25

Please enclose your cheque with this form and return to:

ALS Society of Ontario  
265 Yorkland Blvd. Suite 300  
Toronto, Ontario M2J 1S5



All donations are tax creditable and receipts will be issued.

Charitable Registration # 13182 0938 RR0001

Whatever the gift, it is the circle of connections around those who have lived with or are living with ALS that helps to sustain the work of the Society. Thank you.

0305

A small, handwritten signature in black ink.

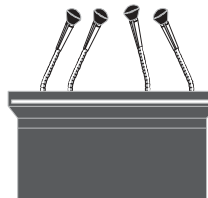
## Guest Speakers Available

Please tell us about opportunities in your community where we can connect with the healthcare community. If you know about an opportunity contact Ravi Jain, our Director of Services, at 1-800-267-4257, extension 216 or via email at [dirtserv@alsont.ca](mailto:dirtserv@alsont.ca).

Volunteers and staff across the province are available to participate in any opportunity to increase awareness and education to those who provide care and service to those living with ALS.

The ALS Society of Ontario education activities include:

- In-service education to healthcare providers in hospitals, long term care facilities and in community service agencies such as home care.
- Presentations at healthcare conferences and workshops.
- North Network telemedicine outreach.
- Displays/exhibits at our equipment vendor/manufacturer conferences.



**The AGM has been scheduled for September 2005 to coordinate with our new fiscal year, which runs from April 1 to March 31.**



ALS SOCIETY OF ONTARIO  
265 Yorkland Boulevard, Suite 300  
Toronto, ON M2J 1S5  
416-497-2267 or 1-800-267-4257  
FAX: 416-497-1256 - [www.alsont.ca](http://www.alsont.ca)

### STAFF DIRECTORY

**Susan Graham Walker - Ext 216**  
Executive Director

**Ravi Jain - Ext 215**  
Director of Services

**Suzanne McDonald - Ext 217**  
Director of Resource Development

**Mimi Haas - Ext 222**  
Executive Assistant/Office Manager

**Irene Grecu - Ext 212**  
Accounting Coordinator

**Chris Forty - Ext 211**  
Client Services Coordinator

**Corina Chevalier - Ext 218**  
Fund Development Coordinator

**Julia Sealey - Ext 210**  
Data Entry Coordinator

**Elena Pochapski - Ext 214**  
Manager of Finance

**Christine ElChiekh - Ext 213**  
Information Service Coordinator  
(Volunteer Position)

### REGIONAL OFFICES

**Ottawa Regional Office**  
613-820-2267  
1-866-858-4226

**Hamilton Regional Office**  
905-540-9746  
1-877-767-0775

**Toronto Regional Office**  
416-497-2267

**Northern Regional Office**  
705-669-0324  
1-888-237-4453

