

Advocacy Award Named to Honour Brett J. Yerex

The Executive Committee of the Board of the ALS Society of Canada is pleased to announce that the Society's advocacy award will be named in honour of Brett J. Yerex.

Brett Yerex, who died in January, was a driving force in the ALS Society's advocacy program at both the national and provincial levels. He helped to shape the organization's messages, introduced the Society to elected officials and participated in every advocacy campaign. As a volunteer he travelled to Ottawa for an ALS Society Hill Day and he was involved in the provincial ALS Society's *a Walk in the Park*.

Brett also made significant contributions to fundraising for services and research

through the Orangeville Walk to D'Feet ALS. He took every opportunity to raise public awareness of ALS.

All of these activities were carried out with passion and humour. A hallmark of Brett's generous style was to give credit to others for achievements that he spearheaded.

The Executive's decision was announced to Brett's family and friends by Susan Graham Walker, Director of Communications, Advocacy & Research Administration, at a memorial service on January 17th.

The Brett J. Yerex Advocacy Award will acknowledge a significant advocacy initiative that has sought to improve the



Brett Yerex (right) and his cousin, Jill Gillis, visit with Peter Adams, M.P. Peterborough, in the spring of 2002

quality of life of people affected by ALS. The ALS Society of Canada recognition awards are given at the Society's Annual General Meeting in May.

ALS Society of Ontario Commits to Ethical Code

On November 22, 2003, the Board of Directors of the ALS Society of Ontario voted to adopt the Ethical Fundraising and Financial Accountability Code. The code, devel-



oped by the Canadian Centre for Philanthropy (CCP), in consultation with charity leaders across Canada, is a set of standards designed to encourage responsible and transparent practice by

charities towards donors, stakeholders and the public.

By adopting this code, the ALS Society of Ontario commits to fundraising

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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.

Putting Your Volunteer Hours to Work

In 2003, volunteers at the provincial office contributed over 1,300 hours! Volunteers across the province collectively contributed thousands more.

Did you know that by recording your volunteer hours, the ALS Society can:

- Use the information to demonstrate to the public the immense contribution volunteers make to the Society.
- Use the information when applying for grants that are dependent or influenced by the amount of time volunteers contribute to the Society.
- Track the growth of services and programs and help measure the success of new programs.

- Identify peak seasons of volunteer involvement.
- Identify volunteers who should be recognized for the amount of time they contribute.

You can help the ALS Society keep track of the number of volunteer hours by going to the volunteer page of the website and downloading a copy of the *Volunteer Hours Tracking Form*. Keep track of how many hours you volunteer during a month and send in your completed form to Helen Taylor, Coordinator of Volunteer Services.

Email: volserv@alsont.ca

Fax: (416) 497-1256

A March of Faces Message from George Goodwin

The *ALS March of Faces Awareness Project* began in the United States in 1997. It is a campaign to create banners for use at ALS events which are designed to increase awareness, and raise funds for care and cure.

In Canada, the March of Faces campaign has been running for almost a year and a half. During that time we have collected in excess of 450 names for the Banners. I would like to encourage those Persons with ALS who would like to appear on the banners to fill out and submit a permission form. The form can be downloaded from www.alsindependence.com. It should be noted that these pic-



tures can and will be made available to the ALS Society to use in its posters.

Each banner includes 20 names and pictures. The vinyl banners, which are 2' wide by 6' long, are an excellent way to raise awareness at ALS functions.

I would like to extend a big thank you to the ALS Society offices, Persons with ALS and families of Persons with ALS for their cooperation. Without you, none of this would have been possible. All the current pictures can be viewed on the ALS Ontario website at www.alsont.ca.

The new & improved ALS ONTARIO WEBSITE

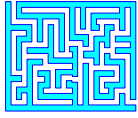
- just a click away 

- Updated pages for people living with ALS and their family
- Community Pages – support group and event information from across the province
- Improved on-line donation process
-  • Section on donation vehicles to support programs and services
-  • Section on ways to volunteer and get involved with the Society in your community

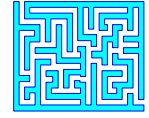
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practices that respect donors' rights to truthful information and to privacy. There is also a commitment to responsibly manage the funds that donors entrust to the Society, and to report financial affairs accurately and completely.

The CCP monitors compliance to the standards outlined in the code. And in committing to these practices, the Society can use the Ethical Code logo as part of its marketing, communication and fundraising strategy to ensure donors and prospective donors that the Society strives to maintain the highest standards in its fundraising activities.



Navigating the Maze



Compassionate Care Benefits for Caregivers

This quarter we introduce you to a new benefits plan for caregivers.

What is the compassionate care benefit plan?

Starting January 4, 2004, compassionate care benefits are a new benefit provided through Employment Insurance (EI). These benefits are meant to support caregivers who often have to take time off work or who have to quit their jobs to care for "a family member who is gravely ill with a significant risk of death" (EI website).

Who is eligible?

Applicants should have accumulated sufficient insured hours and must show that their regular weekly employment earnings have been affected due to the additional responsibility as a caregiver. Benefits are for those who are:

- providing care or support, which includes psychological or emotional support,
- administering third party care
- direct participation in the care of a family member.

A medical certificate must be submitted along with the application. For detailed information on eligibility criteria, please contact your local HRDC office or see contact information given below.

How much will you receive?

At present, compassionate care benefits are available up to a maximum of six weeks. The basic benefit rate is 55% of your average insured earnings subject to the maximum EI limit of \$413 per week. Please note that all income from EI is taxable. You can share the compassionate care benefits with other

eligible members of your family, who must apply for these benefits.

How to apply

Contact your local HRDC office or refer to this website for additional details: http://www.hrdc-drhc.gc.ca/ae-ei/pubs/compassionate_care.shtml.

You can also call HRDC's automated telephone information service number at 1-800-206-7218.

Do you have a question you would like to see addressed in future issues of the JournALS? We encourage you to contact us at:

info@alsont.ca
or
1-800-267-4257, Ext: 215

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

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.

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) _____ Email: _____

I would like 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:

Memorial Giving Special Events Volunteering

Please enclose your cheque with this form and return to:

ALS Society of Ontario
265 Yorkland Blvd. Suite 300
Toronto, Ontario M2J 1S5
1-800-267-4257
www.alsont.ca

All donations are tax creditable and receipts will be issued. Charitable Registration # 13182 0938 RR0001

Welcome to the Team

In November 2003, **Kevin Lee** joined the Society as the Regional Office Coordinator for the Champlain Regional Office. Kevin became involved with the Society as a volunteer when his mother was diagnosed with ALS in October of 2001. Unfortunately Kevin lost his mother a year later. He renewed his commitment to the ALS cause by becoming the Walk to D'feet ALS Family Team Chair in 2003. We are thrilled Kevin has joined the team.

Eileen Hyland is the new Regional Office Coordinator for the Hamilton Regional Office. Eileen has worked as a registered nurse and has held a number of roles in the IT field before providing ALS Ontario with her management experience. Welcome Eileen and best wishes in your work to assist those living with ALS.

After spending two years with ALS Canada, **Charles Hain** has joined the ALS Society of Ontario as the Regional Manager for the Greater Toronto Area. Charles brings his family's experience

with ALS to his work at the Society as well as his fundraising and communications expertise.

The merger of the ALS Societies of Ontario and Toronto has redeployed staff bringing new skills and expertise to the ALS Society of Ontario.

As a member of the regional team, **Wendy Jeffers** continues as the Client Services Coordinator for the Greater Toronto Area. Her experience as a medical secretary and her work in homecare are valuable resources for the Society.

Corina Chevalier has moved to the ALS Society of Ontario as the Fund Development Coordinator. Corina brings with her strong communications and organizational skills. She previously held the roles of Database Coordinator and Event Coordinator with ALS Toronto. She is currently studying Fundraising Management Computer Systems at Humber College.

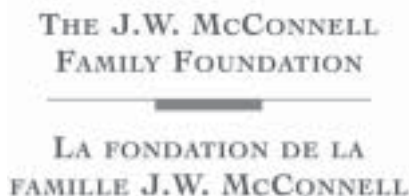
Our Workshop Partners

On March 27th and 28th, 2004 approximately 75 volunteers from across Ontario will participate in "Three Pillars: Supporting the ALS Community". This unique educational opportunity will help build, strengthen and support the services we offer Ontario citizens living with ALS and their families.

A special thank you to the ALS Society of Canada and the J.W. McConnell Family Foundation for encouraging and supporting the development of this volunteer training model.



AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF CANADA
SOCIÉTÉ CANADIENNE DE LA SCLÉROSE LATÉRALE AMYOTROPHIQUE



LA FONDATION DE LA FAMILLE J.W. McCONNELL



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Database Coordinator

Kerry Armstrong - Ext 211
Client Services Coordinator

Helen Taylor - Ext 210
Coordinator of Volunteer Services

Corina Chevalier - Ext 218
Fund Development Coordinator

Nelly Teitelbaum - Ext 214
Finance Manager

Christine ElChiekh - Ext 213
Information Service Manager

REGIONAL OFFICES

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613-820-2267

Hamilton Regional Office
905-540-9746

Toronto Regional Office
416-497-2267

Northern Regional Office
1-888-237-4453

For further contact information please visit our website at www.alsont.ca

The President's Corner



Nigel Van Loan
President
ALS Society of Ontario

I am writing this at the end of a hectic weekend. Many of you know the scenario: well-meaning friends and family have stopped in or stayed over, bringing some welcome cheer, support and even a touch of normalcy to an ALS-afflicted existence. However, at the end of the day, you find that the reservoir of energy has been sorely sapped. This readily brings to my mind that we at ALS Ontario, who also serve and support those with ALS and their caregivers, must be especially careful not to add to their burdens. We must be sensitive to the need, to be crystal clear in our communications and not appear to add to the obstacles and challenges our P'ALS and their caregivers face.

Regretfully, we recently appear to have stumbled in facing that challenge. Elsewhere in this newsletter, you will find an article setting out the reasons why we on the Board of Directors of ALS Ontario, found it essential to change the way in which we support ALS patients who use the services of the Assistive Technology Clinic (ATC) at Sunnybrook. Although we felt that we had no alternative but eventually ceasing to directly fund this Clinic, we wanted to ensure that funding support would still go to the P'ALS who received services from the ATC. However, we did not do a great job at arranging ready alternatives or getting the word out in a timely manner to those affected. We're sorry for that: it added to the burden of those who need that support.

In a similar vein, an article in an earlier JournALS aimed at spreading some good news on the subject of fundraising by ALS **Canada** was apparently open to misinterpretation: it led several people to erroneously conclude that ALS **Ontario** intended to exchange [or sell] our donor list with other charities. We at ALS Ontario have never nor do we

ever in the future intend to trade or sell our donor list, but something in that article — the nuance of Canada versus Ontario perhaps — caused people some grief and for that we apologise.

Your Board of Directors has been working hard through the past year to ensure that the funds that you and others in your name have raised to support the work of the Society have been properly spent. That is, spent in the ways and spirit that you and the donors intended. At times, such as while overseeing and fashioning the recent amalgamation of ALS Toronto and Ontario, this has been truly a challenge and a test of our responsibilities to the members and donors. In the end, we finished the year with our 'financial heads held high'. The programs of support and care for those suffering from ALS in Ontario have been well run and improved upon by the staff of the Toronto and regional offices. So we are doing reasonably well I think. But the two examples cited above, tell me that we must strive to do better still, on your behalf.

New Support Groups

Thanks to the efforts of Pam McFarlin, Lucy Beilier, and Ruth McFeat there are three new Support Groups in Ontario.

Barrie

Support Group for People Living with ALS
Contact Pam MaFarlin at 705-728-8191.

Kitchener-Waterloo

Support Group for People Living with ALS
Contact Helen Taylor at 1-800-267-4257 ext 210 or volserv@alsont.ca

London

Caregiver Support Group
Contact Ruth McFeat at 519-762-3516.

The time and location of these support groups and others around the province can be found on the Community Pages of the ALS website (alsont.ca).



Drug Trial Update

A study sponsored by Novartis is currently taking place across the country to test a new drug, TCH346. This study is to evaluate the safety and clinical effects of TCH346 in patients at the mild or mild to moderate stages of ALS.

In Ontario, there are trials are being conducted by:

- Dr. Neil Cashman at Sunnybrook and Women's College Health Sciences Centre in Toronto,
- Dr. Michael Strong at the London Health Sciences Centre and
- Dr. John Turnbull at the Hamilton Health Sciences Centre.

If you have questions about this new drug or the trial ask your neurologist.

Shifting Service Priorities:

An Update on the Assistive Technology Clinic, Toronto

As of January 1, 2004 the ALS Society of Ontario stopped funding for the Assistive Technology Clinic at Sunnybrook and Women's College Health Sciences Centre. At the same time the ATC implemented a fee-for-service structure that caused significant alarm, not only to the persons with ALS scheduled to attend the Clinic, but also to the ALS Society's Board.

In response, the Board agreed to fund an additional \$18,000 in direct funding to the ATC, to cover from January to March, 2004 with the hopes that this will give the ATC an opportunity to attract funding from alternate sources.

The ATC, a private business enterprise, was originally started in 1994 with funding from the ALS Society of Toronto to meet gaps in services not available for communication technology in the community. Few clinics at that time were able to meet the rapidly changing needs of the person with ALS in order to maintain independence through the course of their disease. During the first couple of years the ALS Society met with the Ministry of Health Assistive Devices Program (ADP) and secured additional funding for the clinic, in conjunction with funding secured by the ATC with the assistance of the Sunnybrook Foundation.

The funding of the ATC by ALS Toronto was intended to be short-term in duration and all expected that the ATC

would eventually be fully funded by the government and/or Sunnybrook Hospital. Unfortunately this other funding did not materialize, and ALS Toronto struggled to maintain its annual commitment of \$72,000 per year in direct funding to the ATC.

Therefore, the Society began communicating with the ATC and with the Ministry of Health and Sunnybrook & Women's College Health Sciences Centre in mid 2003, to inform them that the Society's ability to fund the Clinic beyond 2003 was in serious jeopardy. The message from the Society and ATC was to urge Sunnybrook and the Ministry to begin funding this clinic as quickly as possible.

With the approaching merger of the ALS Societies of Ontario and Toronto and in order to realize the long-term advantageous effect of this move, the ALS Ontario board, in the short-term, realized that some restructuring was necessary in order to consolidate operations, generate additional revenues and decrease duplication of programs and services potentially available from the community that may have been provided by the ATC.

By November 2003 no additional funding was forthcoming from the Ministry or Sunnybrook and therefore the Board of Directors of ALS Ontario made the difficult decision to cut the direct funding to the ATC in order to balance its 2004 budget.

Mindful of the potential consequences, the Board entered into discussions with the ATC about ways to mitigate the impact on persons with ALS, and also began exploring alternative services elsewhere in the province.

The funding extension provided by the ALS Society of Ontario will give the ALS Society and persons with ALS in Ontario some time to develop alternative mechanisms for services and for funding. By April 1, 2004, if no additional funding is identified, the ATC will re-institute its fee-for-service structure. At that time the ATC and the Society will communicate together to inform you of funding alternatives.

The ALS Society of Ontario will continue to explore avenues of funding that directly supports the person with ALS, that does not duplicate services available in the community and that enhances the quality of life of those living with ALS. The Society is committed to enhancing independence, dignity and hope through the Equipment Loan and Purchase Assistance Program, through education, through providing networks of support through chapters across the province and through research into the cause of ALS.

We appreciate your patience and understanding as we deal with this vital and complex situation. If you have any questions about this issue, please contact our Director of Services, Ravi Jain at dirtserv@alsont.ca, or at 1-800-267-4257, ext. 215.

Privacy Policy

The ALS Society of Ontario respects your privacy. We protect your personal information and adhere to all legislative requirements with respect to protecting privacy. We do not rent, sell or trade our mailing lists. The information you provide will be used to deliver services and to keep you informed and up to date on the activities of the ALS Society of Ontario, including programs, services, special events, funding needs, opportunities to volunteer or to give, open houses and more thorough periodic contacts. If at any time you wish to be removed from any of these contacts simply contact us at 1-800-267-4257 extension 217 or via email at info@alsont.ca, and we will gladly accommodate your request.