

Amyotrophic Lateral Sclerosis
Society of Ontario

2003 ANNUAL REPORT



Helping people with ALS to live with independence, dignity and hope.



MISSION

To help persons living with ALS and their families manage the effects of the disease and to raise money for ALS research.

VISION

Until a cure is found, our vision is a world where persons living with ALS realize their full potential in a society which respects their rights and dignity.

VALUES

We respect the confidentiality of the people whom we serve.

We respect the decisions related to quality of life made by people living with ALS.

We endeavour to apply best practices to our services.

We value the provision of comprehensive information about: ALS, services of the ALS Society, resources and options for health care professionals and other needs of people living with ALS.

We respect the right of persons living with ALS to live with dignity.

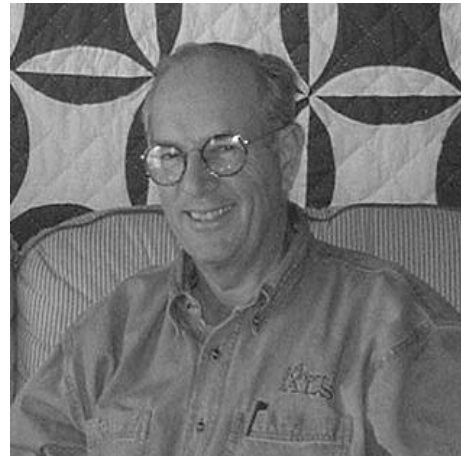
We will work to secure community support for persons living with ALS.

Helping people with ALS to live with independence, dignity and hope.

President's Message 2003

From the Desk of Nigel Van Loan

One year ago, at the first meeting of the new Board of Directors of ALS Ontario, the meeting at which I was appointed as the President, we fully expected to face a 'typical' year of some small challenges and, hopefully, some larger chances to make good progress. Little did we anticipate that within a few short weeks we would have to confront the necessity of integrating ALS Toronto into our fold in a way that maintained a high quality of support to P'ALS throughout the Province while ensuring the continuing financial viability of the Society. But that was exactly how we spent the majority of the next six months.



The fact that we closed the year with a notably improved support programme yet with only a very modest deficit testifies to the success of the efforts of all. While the Board and the Executive effectively oversaw the process, the Executive Director, Karen Ormerod, and her staff in Toronto and at Regions made sure that the day-to-day activities proceeded without interruption and that the transition was smooth. Indeed, our operations were seen by many to improve on most fronts over this testing period. Volunteers at Chapters across the Province did more than we could have hoped for: most important was their unceasing travail in direct support of P'ALS. But they also led and conducted Walks and other special events such as Concerts and Cornflower sales.

Revenues from these continued to grow dramatically, enabling more funds to flow to research and for our equipment support to grow apace with demand. In the latter area it is worth noting that a recent study by an outside agency stated "ALS Ontario has been able to develop its equipment program into a core competency. While several other not-for-profit organizations deliver similar equipment ... none have the ability that ALS Ontario possesses to recognize and respond effectively to the rapidly changing needs of P'ALS."

Therefore, as our organizational year draws to a close, we can take a brief pause to reflect upon the success of our efforts, draw a deep breath and face the challenges that await anew. Of some we are already aware: the unremitting need to provide aid to P'ALS and caregivers; the constant requirement to recognize and to gain support from donors and volunteers; and the nurturing of good staff -- headed by the quest for a new Executive Director. Others we cannot foresee but, just like this past year, some surprises doubtless await. With the same, fine work we can master the new year.

A Message from the Executive Director



Dear friends and colleagues – this report is much more difficult for me to write, in light of the fact that I will be leaving the Society in two weeks to take up a new career challenge as President & CEO of the Osteoporosis Society of Canada. While naturally I am excited about this next phase of my career, I am just now starting to feel the tremendous sense of loss that will accompany my departure. These last five years have been so very important to me – I know that I will not let go quickly nor easily.

But what a five years it has been! I recall, on my first day of employment (November 28, 1998) learning that while I had accepted the position of Executive Director for the ALS Society of Ontario, that did not include Toronto! I was stunned and seriously questioned whether or not I could succeed in such a situation. However, I am not a quitter, and so I told myself that I would give it a year to see if I could make a difference – and if not, then I would move on. Well, there was no turning back.

Back then there were 17 Chapters and Support Groups, all operating independently and autonomously – doing a fabulous job for those with ALS in their geographic areas. But what we soon realized was that in areas where there was no chapter, little or no services were available. We had sadly inadequate computer systems and software, and insufficient staff to meet the needs and demands. We didn't even know how many people we were serving – there was no provincial database of people with ALS, or even of the equipment that we loaned out.

And look where we are now! With stronger Chapters (or Community Councils), and a well-trained staff team working out of four regional offices, we have transformed the Society. Working together, the volunteers and staff have constructed a more vibrant ALS Society of Ontario, where now more than 80% of all equipment requests are delivered to the patients' homes in 10 calendar days or less! Our phenomenally successful Walks to D'feet ALS have given us the financial resources we so desperately needed – and have given rise to unprecedented levels of awareness too.

These successes came just in time – for the first time ever, in 2003 we saw more people register with the Society than passed away – resulting in an increase in the number of patients served. Sadly this trend is continuing – we registered 81 patients in the first three months of 2004. But 2003 was mostly a year of consolidation – we tested and fully implemented our new fundraising and accounting databases and trained our regional managers. The Northern Regional office was opened in Sudbury in March 2003, and quickly proved to be a successful venture.

Finally, the amalgamation of the ALS Societies of Ontario and Toronto took up most of my efforts last year. I can't tell you how proud I am of the volunteers and staff who took up this challenge and made it happen. Certainly, it was something not even foreseen back in 1998, but it was something that needed to happen. The amalgamation was the final piece in the reconstruction of the ALS Society of Ontario – and it is an achievement of which we should all be proud.

People with ALS and their families are served by volunteers and staff who have no parallel. It has been an honour and a privilege to work and grow with them. We have supported each other through good times and bad – with always the ultimate goal of improving the lives of persons with ALS while we search for a cure. I will never forget these years – they count among the very, very best of my career and of my life.

Sincerely, Karen L. Ormerod

2003 Support Services to People Living with ALS

Two thousand and three was a year in which we improved efficiency and effectiveness of our primary program for people living with ALS – the Equipment program. At the same time we surveyed those living with ALS to provide information that will enable us to benchmark our progress and to enhance and expand our services in the future.

Administrative and operational procedures were solidified at both the provincial and regional offices and so by the end of 2003 both were fully utilizing our database to track equipment. Each of our approximately 1,000 pieces of equipment is now labeled to ensure that equipment is accurately tracked and accessible at all levels of the organization through a virtual private network.

In order to ensure timely delivery of equipment that is well maintained, the Society has entered into contractual agreements with equipment suppliers across the province. In total, we work with 15 different equipment locations that store, deliver, maintain and assist clients with learning how to use a variety of equipment when delivered to their home.

Turnaround time for requests to our equipment program has dramatically improved in 2003. During the last six months, we were able to complete just over 80% of the requests within 2 weeks of receiving the application from a health care professional.

Support services expenditures to ship, store, repair, lease and purchase equipment was up 17% over 2002 for a total of \$611,560. Of this total expenditure \$180,000 was spent on purchasing equipment such as lift equipment, respiratory equipment and hospital beds and mattresses. Equipment leases primarily for communication devices were higher by 25% to \$16,274 in 2003.

In 2003, we met 575 requests for equipment of which approximately 63% of approved requests were met through loan of equipment from our inventory. The balance of these requests were provided through funding assistance. Approximately half of the equipment funded was on a cost share basis, where we paid 65% of the cost and the client paid 35%, while the rest were 100% funded by the ALS Society.

It is vital that we continually improve the efficiency of the equipment program as in 2003 we saw a noticeable increase in the number of people with ALS registering with the Society – up 14% over 2002. Early 2004 figures indicate similar trends. Beginning in 2004 the ALS Society of Toronto merged with the ALS Society of Ontario. Clients of ALS Society of Toronto are now included within the Ontario support services policy framework. As a result, about 225 Toronto-based clients have been added to our client database.

Information and education about ALS is vital to those living with ALS in order to plan care during the progression of the disease. Central to the development of a care plan are health care professionals in the community. We continue our efforts to educate and inform these health care professionals through in-service presentations, dissemination of educational material to agencies and health care facilities and through our website.

Advocacy efforts at the community level on behalf of clients also help create better awareness amongst health care professionals. In a larger context, the people living with ALS in Ontario participated in the In Synchrony Project. Very little research or work has been done on the specific issues of progressive disabilities (rather than disabilities as being static in nature) and the In Synchrony Project was created to

ensure that issues related to progressive disabilities are included in the development of disability supports and policies at the provincial and federal government levels.

The 2003 Support Services Survey was circulated towards the end of 2003 to clients all across the province, including the Toronto area. Five hundred and ninety surveys were mailed with a response rate of 28%. With the assistance of MBA students from Schulich School of Business we have tabulated the results and further analysis being conducted in preparation for an organizational strategic planning session late in 2004.

Thank you to the Support Services Committee for their guidance, dedication and commitment to helping those living with ALS through the ongoing monitoring of our support services programs: Monica Menecola, Chair; Marvin Streich, Former Caregiver, Sudbury; Jane Verner, Social Work Department, St. Mary's of the Lake Hospital, Kingston; Susan Carroll-Thomas, Speech Language Pathologist, Ottawa Rehab Centre; Cheryl Flanders, Case Manager/R.N, Durham Access to Care; Nigel Van Loan, Caregiver, Ottawa; Nancy Harvey, Occupational Therapist.

Ravi Jain, Director of Services



Equipment from our loan program enables someone with ALS to remain a part of his or her community. Here Tony, his daughter and a volunteer from the Society enjoy the opportunity to share in the success of the Walk to D'feet ALS in raising funds for services and research.

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2003 Support to Volunteers

In 2003, the ALS Society of Ontario made volunteer development a priority. To create new opportunities and expand volunteer involvement, the ALS Society has developed a new model for volunteer participation called “Community Councils”, a new model for training these volunteers called “Pillars of ALS Volunteer Training” and a new resource called the “Community Resource Manual.”



Duncan MacKinnon (left) and Garret and Mary Anne Walsh at The Pillars of ALS Volunteer Training weekend.

The program is based on three Pillars: Support Services, Advocacy and Awareness and Fund Development and the knowledge that strong leadership will strengthen and build each pillar. The goal of the program is to support volunteer’s work on a day to day basis in their community.

The development of the volunteer program and the changes to the volunteer structure at the grass roots level will give current volunteers the tools, knowledge, skills and ability to run more effective programs, support and increase their volunteer base and to communicate effectively and work with other community volunteers and staff members.

In March of 2004 the “Pillars of ALS Volunteer Training” was held in Toronto supported by grants from the ALS Society of Canada and McConnell Family Foundation. It brought together forty volunteers from across Ontario, many new to the organization and some from communities without a chapter. It was not only an opportunity to start implementing the program but a wonderful chance for volunteers to meet their peers and build friendships and support.

The following volunteer comments capture the benefits and impact the creation and implementation of this volunteer program has had already: *“I realize just how far we [the ALS Society] have come in seven years; I feel as if I have a “second wind; It is an opportunity to understand more fully the use of the dollars raised and the need to be better informed; I think our Chapter needs to examine valuable changes; Definitely reassured that I am doing the right thing and how to improve and utilize the ALS Society resources; I’m even more prepared to go out there and tell my story.”*

The move toward training and subsequent work to create regional workshops is the Society’s way of showing their commitment to investing in communities across the province.

Thank you to all of the amazing volunteers whose dedication and commitment make it possible for the people with ALS to live their lives with independence, dignity and hope.

Helen Taylor, Coordinator of Volunteer Services

Fundraising for Care and Cure

Once again volunteers working in communities across the province have been instrumental in our ability to provide improved level of services to families living with ALS. Golf tournaments, dances, dinners, concerts and walks have flourished bringing new support for and greater awareness of the day to day challenges of living with ALS.

The Walk to D'feet ALS and local walks have been instrumental in these increased levels of services and hope. In 2003 volunteers organized a total of 17 walks raising over \$817,000, a 29% increase over 2002 figures! With the addition of Toronto numbers over \$960,000 was raised in the province! This translates into over \$280,000 contributed to research conducted into finding a cure for ALS. In addition, we have been able to increase the level of services as seen by an increase of 17% from 2002 in the level of equipment provided to people with ALS through our equipment program.

We are grateful to the following dedicated volunteers who rally teams of family and friends in their communities to organize the Walk to D'feet ALS:

Marjorie Miedema, Alliston	Pamela McFarlin, Barrie
Cindy Rymes, Belleville	Julie Wamsley, Cobourg
Carol Burgess, Durham	Marion Irwin, Durham
Bruce Wilson, Hamilton	Marilyn Patterson, Hamilton
Celine Zakos, Kingston	Steve Thomas, London
Dora Redman, London	Bill Muirhead, Niagara Falls
Helen Sherrard, Orangeville	Sonya Harwood, Ottawa
Kathryn Johns, Peterborough	Deb Timperio, Peterborough
Sandra Burson, Smiths Falls	David A. Salter, Sudbury
Marvin Streich, Sudbury	Lorne Kondreska, Thunder Bay
Lynn Frenette, Orangeville	Phyllis Goodfellow, Toronto
Barbara Hopkin, Toronto	Bonnie McClenaghan, Sault Ste. Marie
Richard Birchall, Mississauga	Sharon Babineau, Hamilton

In its fourth year Elizabeth's Concert of Hope reached a milestone – over \$1 million dollars raised! In addition, Elizabeth's Concert of Hope, in honour of Tim Noel, expanded to Ottawa where community support was astonishing in support of vital services to those living with ALS. Proceeds from these two events will also be divided between services and research.

The ALS Society of Ontario is also grateful to the many volunteers who organize additional events in their communities throughout the year. Without their ongoing dedication and passion for increasing awareness about ALS and raising funds, we would not be able to contribute to improved quality of life.

In 2004 we will once again see an expansion of the Walk to D'feet ALS with the addition of four new walks. In addition we will be diversifying our fundraising strategies with the addition of new programs to increase donor support through these initiatives.

Suzanne McDonald, Director of Resource Development

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Thank You For Your Support



The ALS Society of Ontario currently receives no government funding, therefore we rely solely on generous donors and events organized by volunteers. We are so very grateful to the following for their individual donations in excess of \$1,000.

Corporate/Foundation/Other

A.G.E Ecole Secondaire Catholique L'Horizon	A.N.A.F. Ladies Auxiliary	ACE INA Insurance
ACT Teleconferencing Canada Inc	AmeriCredit	Apollo Management Services
Bailey Metal Products Limited	Bikers Fighting ALS	B'nai B'rith Foundation
Brantford Community Foundation	Brico Transportation Services Ltd.	Brougham Specialty Advertising
Casino Niagara Cares	CIBC Charitable Foundation	City of Ottawa
Cobourg Cougars Junior A Hockey Club	Coin Canada	Colliers International
Compuquest 2000	Contract Furniture Source Inc.	Credit Union Central of Ontario
Dominion of Canada General Insurance Co.	Durham Instruments	Fenwick Automotive Products
Fidelity Investments Canada Ltd.	Fountain of Hope	GBA(ROH-OTTAWA)INC
Gunners Club	Halsall Associates Limited	Harwood Fire Fighters Association
Huntley Curling Club	Huntley Curling Club Bonspiel	IBM Employees' Charitable Fund
Kiwanis Club of Barrie- Bingo Account	Levi Home Hardware	Lioness Club
Local 7175 United Steel Workers of America	Local Heroes II Inc.	McDonald's Restaurants of Canada
Midtown Storage Ltd.	Milton & Ethel Hams Family Foundation	Novatech Engineering Consultants Ltd.
Morneau Sobeco	Mr. Handyman of Ottawa	Oxford Sand & Gravel
Ottawa Congress Centre	Ottawa Construction Association	Progeny Management
Pottruff & Smith Insurance Brokers Inc.	PriceWaterhouseCoopers	RBC Foundation
Promitus Solutions Ltd.	Proper Ford	Royal Canadian Legion Branch 90
RCMP	Rotary Club of Brampton	Service Master of Ottawa
Royal Ottawa Golf Club	Scotiabank	SiberCore Technologies
Shedden Mission Fast Pick Ball Team	Shoppers Drug Mart	The Great-West Life Assurance Co.
Steve and Sally Stavro Foundation	Summit Restoration	Trillium Home LOBA of Ontario West
The McQuillan Group	Trillium 200 Seniors Club	Westbrook Floral
Trophy Case Restaurant	Venture Steel	Workflow Innovation
Warehouse Diner	Wescast Industries Inc.	

Individuals

Gino Bellisario	Joan Berggren	Don Berggren	Dorothy Curtis
Diane Demorest	Mr. & Mrs. Deverett	Andrew Douglas	Bill Johnstone
Roy Hewson	A. Hosie	David Hunt	Marshall Kesten
Bruce Langstaff	Louise Levesque	Robert E. Luke	Cassan MacLean
Mary Ann McFadyen	Donald McKillop	John Melcher	Helen Nathanson
Betty Potts	Paul Phoenix	Lana Reid	Jordan Sheridan
Peter Sloan	David Smith	Mike Sribney	Ken Sutherland
Luisa Ward	Barry Watt	David Williams	Rod Winger
Yonatan Wisebrod			

Bequests

The Estate of Anne Kucharski	The Estate of Ruth Selby	The Estate of Arthur Marshall
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Events

We would also like to acknowledge the following individuals and families who held events across the province:

Andy Stoikos	Tom St. Onge	Cathy Ratchford	Jackie Maz and Laurie Wells
Laurie Martindale	Cissy Peters	Padraig Cosgrove	Stanley Isherwood
Barbara Balicki	Noreen Smith	Mary De Vries	Ray & Linda Wreaks
Barry Watt	Terry Keyes	Claudio Peloso	Sister Edna & Loretto Abbey School
Jacques Boulet			

Helping people with ALS to live with independence, dignity and hope.

ALS SOCIETY OF ONTARIO FINANCIAL STATEMENTS
DECEMBER 31, 2003
(Excerpted from Auditor's Report – Deloitte & Touche)

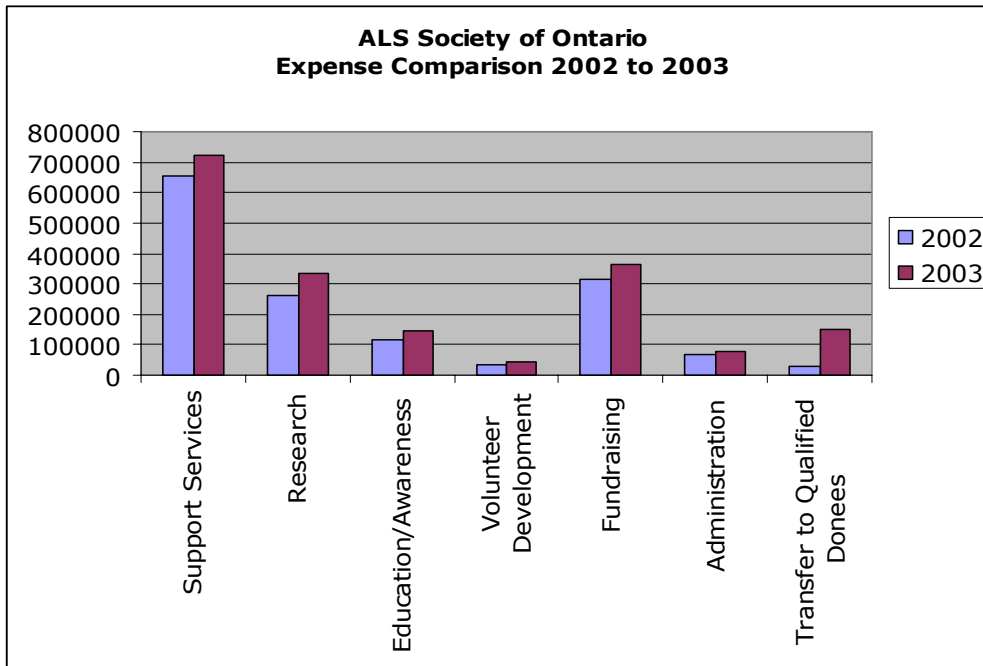
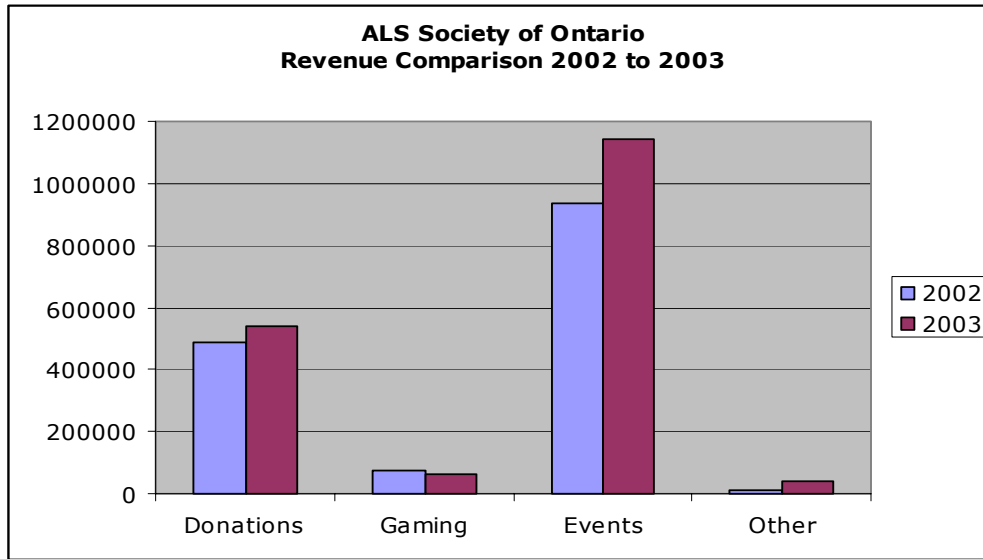
CONSOLIDATED BALANCE SHEET

	2003	2002
ASSETS		
CURRENT		
Cash	\$723,254	\$472,842
Accounts Receivable	9,340	12,657
Prepaid Expenses and Supplies	30,849	21,963
	763,443	507,462
LONG-TERM INVESTMENTS	481,124	459,438
CAPITAL ASSETS	230,404	190,170
	\$1,474,971	\$1,157,070
LIABILITIES		
CURRENT		
Accounts Payable and Accrued Liabilities	\$167,007	\$73,351
Due to ALS Canada	282,262	18,200
Deferred Revenue	10,000	--
	459,269	91,551
NET ASSETS		
GENERAL FUND		
Invested in Capital Assets	230,404	190,170
Other	583,995	655,759
RESTRICTED FUNDS		
Eva Farkas Memorial Fund	54,270	74,157
Regional Development Fund	150,000	150,000
ADINA BEN PORAT ENDOWMENT FUND	(2,967)	(4,567)
	1,015,702	1,065,519
	\$1,474,971	\$1,157,070

CONSOLIDATED STATEMENT OF OPERATIONS
Year Ended December 31, 2003

	2003	2002
REVENUES		
Donations		
Cash	\$415,589	\$310,646
In Kind	122,074	179,672
Provincial Nevada (Gaming) (Net)	45,440	51,788
Special Events	1,140,475	934,020
Interest	19,374	9,250
Bingo (Net)	19,642	20,614
Government Grant	11,799	--
Other	11,243	4,275
	1,785,636	1,510,265
EXPENSES		
Support Services	459,905	418,771
Research (ALS Canada)	334,257	261,124
Administration	79,405	68,918
Volunteer Development	42,329	35,759
Fundraising	366,022	314,533
Education & Public Awareness	143,267	115,158
Transfer to Qualified Donee	148,008	29,013
Assistive Technology Clinic	24,000	24,000
Amortization of Capital Assets	238,260	212,211
	1,835,453	1,479,487
NET EXCESS OR (DEFICIENCY) OF REVENUES		
OVER EXPENSES FOR THE YEAR	\$(49,817)	\$30,778

2002-2003 Revenue and Expense Comparisons



The ALS Society of Ontario Staff Team

Karen L. Ormerod, Executive Director
Ravi Jain, Director of Services
Suzanne McDonald, Director of Resource Development
Christine Forty, Client Services Coordinator
Nelly Teitelbaum, Finance Manager
Helen Taylor, Coordinator of Volunteer Services
Sara Lawson, Executive Assistant/Office Manager
Corina Chevalier, Fund Development Coordinator
Irene Grecu, Accounting Coordinator

Regional Units

Champlain Region, Nepean
Marion Williams, Regional Manager and Kevin Lee, Regional Office Coordinator
Hamilton/Niagara/Brant Regional Office, Hamilton
Sharon Babineau, Regional Manager and Olana Lytwyn-Morris, Regional Office Coordinator
Donna Makela – Northern Ontario Regional Office, Sudbury
Greater Toronto & Area, Toronto
Charles Hain, Regional Manager and Wendy Jeffers, Client Services Coordinator



Volunteers in Durham prepare signs for each of the teams participating in the Walk to D'feet ALS.



Family teams are the key to success for the Walk to D'feet ALS. Barrie 2003.



CITY-TV personality Roger Petersen hosted the 2003 Toronto gala. Actor Wendy Crewson (second from the right) is pictured here with committee members Mary Lynne Stewart and Suzanne McDonald.

ALS Society of Ontario
BOARD OF DIRECTORS

President
Nigel Van Loan, Ottawa

Vice President
Grace Burns, Pickering

Treasurer/Secretary
Chris Nutt, Oshawa

Ombudsperson/Legal Advisor
Katherine Pollock, Toronto

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Kathryn Johns, Peterborough
Dr. Mahmoud Ali, Burlington
Ted Kelterborn, Toronto
John Payzant, Toronto Unit Representative

Sector Representatives

East – David Robertson, Ottawa
East Central – Pam McFarlin, Barrie
North – Lorne Kondreska, Thunder Bay
West Central – Janet James, Burlington
West – Ruth McFeat, London

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Simcoe/York Region – Pam McFarlin, Chair
Northern Region – Lorne Kondreska, Thunder Bay
Thames Valley Region – Ruth McFeat, London
Hamilton/Niagara/Grand River Region – Janet James, Burlington
Essex/Kent/Lambton Region – Vacant
Waterloo/Wellington/Dufferin/Grey/Bruce – Vacant
Durham Region – Barbara Johns, Peterborough
Quinte/Kingston/Rideau Region – Vacant
Champlain Region – David Robertson, Ottawa



AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF ONTARIO
SOCIÉTÉ ONTARIENNE DE LA SCLÉROSE LATÉRALE AMYOTROPHIQUE

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