

AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF ALBERTA AND NWT



Annual Report 2004

The Amyotrophic Lateral Sclerosis Society of Alberta is dedicated to making everyday the best possible day for people with ALS by providing support, facilitating the provision of care, promoting awareness and helping find a cure.

**AMYOTROPHIC LATERAL SCLEROSIS SOCIETY
OF ALBERTA AND NWT**

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ALS SOCIETY OF ALBERTA

Vision

Through increased, province-wide awareness, provide hope and access to equitable levels of support for people affected by ALS.

The courage of those affected by ALS is the inspiration that drives the work of the ALS Society of Alberta. The greatest challenge is to find ways of ensuring that support and services are available to everyone who lives with ALS, no matter where they live in Alberta or NWT. The scope and breadth of the work that the ALS Society of Alberta is engaged in would never be possible without the dedication of countless volunteers, the generosity of donors, the unique knowledge and abilities of the staff and most importantly, those with ALS who provide us with knowledge, leadership and inspiration.

Tim Stauff, Chair, ALS Society of Alberta

Janice Hagel, ALS Clinic Coordinator, Calgary shared the following after a phone call from a woman whose mother had died of ALS.

... wanted to say thanks on behalf of herself and her mom for the 'thorough, kind and good care her mom, and her family received'. She said she has been meaning to call for months, but found it too difficult until now. She said she felt we really 'made a difference' to her and her family throughout the course of her mom's illness...from diagnosis, to coping, to dying well. She also said she felt like we "were an anchor in a sea of uncontrollables".

We appreciate knowing that we are doing what we try really hard to do.
Kudos to you all!!!

Values

RESPECT

ACCOUNTABILITY

CARING

PASSION

SERVICE

QUALITY OF LIFE

The Cornflower: A Symbol for ALS

The Cornflower symbolizes courage. Despite its fragile appearance, it can withstand both frost and drought. Its peaceful, strong blue colour never fades, no matter what it faces. People with ALS show tremendous courage and strength of character to cope with the devastating changes that occur to their bodies.

As you pin on your cornflower, remember not just those affected by ALS, but also all those who give of themselves, each in their own unique way, to help us "...make everyday the best possible day for people with ALS..."

THANK YOU AND FAREWELL LOIS HOLE, LIEUTENANT GOVERNOR (1933 – 2005)



"The heart and soul of Alberta doesn't lie in the rich farmland, the majestic Rockies, the precious oilfields or bustling cities. As wondrous and important as those features may be, that heart resides in our people."

***The Honourable
Dr. Lois E. Hole, C.M., A.O.E.
Lieutenant Governor of Alberta***

As you enjoy the colours and the smells and yes, even the work of gardening this spring, remember Lois Hole. As the Lieutenant Governor, The Honourable Dr. Lois E. Hole, C.M., A.O.E. was Patron of the ALS Society of Alberta. Her warmth and compassionate caring nature supported and encouraged all of us and the ALS Society of Alberta is truly honoured to have been associated with her.

MILESTONES - 2004

ALS AB Advocacy Initiatives: Over a year in the planning, the ALS Society 'Day at the Legislature' was held on April 26th 2004 when 50+ staff and volunteers met with 49 MLA's at the Alberta Legislature in Edmonton.

Preparation was intensely focused and included training in the purpose of Advocacy 'to influence government policy changes and decision making'.

Analysis of the survey mailed to persons with ALS, caregivers, and volunteers indicated that the main concerns fell under the umbrella of 'Equity of Access to Services'. The main areas of policy influence to be targeted were:

- Equal access to respiratory support – assessment and provision of BiPap;
- Equity of access to Self Managed Care Funding across the province and within health regions;
- Access to Speech Language Pathologist Services and provision of communication devices, and
- Training requirements – institutional and community based workers

The Minister of Health and Wellness invited us to make contact with his office for follow up. Since then meetings have been held with the Standing Policy Committee on Health, Alberta Health and Wellness, Population Health and the Capital Health Authority.

While change is slow to come, we have seen evidence of increased interest and support at the Provincial Government level and positive relationships are being developed.

The ALS AB Organizational Assessment: This assessment was completed with the help of the Calgary Center for Non-Profit Management. Areas reviewed included governance, fund development, financial management, human resource / volunteer management and information & communication technologies. The Organizational review resulted in a full day of planning in early September. The day was facilitated by David Sheridan - with the financial support of ALS Canada – and resulted in a do-able plan that will guide the work of the Society for the next year and beyond.

HIGHLIGHTS FROM 2004

Client Services: The demand for services is ever increasing but the efforts are clearly appreciated by both those living with ALS and healthcare professionals across the province. Services were provided to 186 clients in 2004. The goal of the ALS AB Client Services Program is: "To be a seamless web of integrated support for the client and their family with all involved agencies".

"Patricia and all involved -Firstly we must thank you for all the concern and caring for Paul (and all who suffer with this hideous disease). It was such an encouraging feeling to know that there is such a strong organization behind us, and we are very grateful for the help and support you gave."

Joan Beland, Grande Cache, mother of Paul Beland

Client Equipment Program: This program, which includes both mobility equipment and adaptive and augmentative communication devices (AACD), currently manages 1105 pieces of equipment with a value (after depreciation) of \$538,866. The inventory includes power and manual wheelchairs, electric hospital beds, ceiling track lifts and specialized mattresses as well as laptop computers, environmental control switches, laser pens and letter boards.

In the fall of 2004, ALS AB worked with a group of nursing students from the University of Calgary to identify ways to best meet the AACD needs of people with ALS, specifically in Calgary and Southern Alberta. Their findings will help to guide our work as we continue to refine the program.

"... people with ALS don't have time to wait, and that the speed with which care, equipment and services were given was phenomenal. She finished off by saying we (the ALS Team) are a 'remarkable community'."

From a call shared by Janice Hagel, ALS Clinic Coordinator, Calgary

End of Life Care and ALS: Patricia Ordynec and Jane Rivest have presented these in-services several times to healthcare professionals throughout central Alberta. Both the information and the presenters have been highly praised by participants. Clearly there is a need for the information and recognition of the value and credibility of the ALS Society of Alberta.

"Patricia - I want to express my appreciation for your assistance to Dianne and Rob. It was evident how helpful you were to them in a practical way, and Rob certainly made it clear how much they both enjoyed your visits. Thank you for being there. Personally I was grateful for your presence and expertise on the day Dianne died, and later that week. It helped to make the end of her life the way she wanted it, and you comforted all of us".

Linda Zwicker - Toronto - who visited her sister here, at the end.

HIGHLIGHTS FROM 2004

(Continued)

Resource Development and Communication: 2004 was a successful year for fundraising, in spite of some unexpected challenges. Notwithstanding the fact that the position of Resource Development was either vacant or in transition for much of 2004, the help of the dedicated Betty's Run and Walk to D'feet ALS volunteers helped to ensure that those events were once again very successful. In October ALS AB was thrilled to welcome Wayne Steer to the position of Manager, Resource Development; in addition to resource development his duties also include considerable communication responsibilities including development of the new ALSAB website at www.alsab.ca as well as some of the volunteer management activities within the Society. Thank you Wayne, for taking on the challenge.

Our Progress Over the Past Six Years

Historic figures may help to shed some light on the advances the ALS Society of Alberta has made to improve the breadth and scope of services we provide to Albertans.

	1998* ²	2004* ³	Increases
Alberta Population * ¹	2,764,670	3,056,700	11%
Estimated # of Alberta PALS * ⁴ * ⁵	194	214	10%
Average # of PALS Receiving Services	90	130	44%
% of Alberta PALS Helped	46.39%	60.75%	31%
Total Budget of ALS Society of Alberta	\$ 211,262	\$ 786,049	272%
Categories of Service as % of Total Budget for ALS Society of Alberta			
Research \$ Sent from Alberta	16.57%	19.19%	16%
Awareness & Education	3.76%	4.90%	30%
Client Equipment	1.36%	31.45%	2214%
Client Services	16.04%	32.22%	101%
Advocacy	0%	1.48%	Infinite

*¹ – Extrapolated value from Government of Alberta Official Statistics and Public Health Association "Resolution 4: A Call for Standards to Mandated Public Health Information for Non-English Speaking Albertans"

*² – 1998 Financial Numbers taken from 1999 audited financial statements for the ALS Society of Alberta.

*³ – 2004 Financial Numbers taken from the 2004 Budget for the ALS Society of Alberta.

*⁴ – Based on 7/100,000 incidence rate of disease in Alberta.

*⁵ – PALS – People with ALS

ALS Partners: In June of 2004, in conjunction with the ALS Day presented by the Canadian Congress of Neurological Sciences (CCNS), ALS AB hosted the first national Client Services Day that included staff from several ALS Units as well as Clinics across Canada. The most powerful message we heard was not from a neurologist or other health care professional but from Chris Mann, a Calgarian with ALS. He was asked to speak on "The 5 things I want my neurologist to know". He began by telling us that there are not five things that are important, only one. *"It's not about dying with ALS, It's about living with ALS."* Thank you Chris, for all you have taught us.

“Amyotrophic Lateral Sclerosis”

ALS

It tears you up it makes you cry
You watch your loved one want to die
They want to move, they want to smile
They can't; because they're immobile

They want to hug they want to kiss
They want to experience life's true bliss
They know the world is passing by
They also know they're going to die

They are really trying hard to adapt
But in their body they are trapped
Muscle by muscle day by day
They would give anything for one more day

Every day two or three
Disappear from you and me
Who is the one who steals away
Life after life in this wretched way?

ALS

By Courtney Keen

Courtney, who will be 15 in June 2005, attends Vincent Massey Junior High School in Calgary, Alberta. Courtney's Language Arts teacher assigned a project to read and report on an autobiography. She chose to read, ***“Laugh I Thought I'd Die”*** by **Dennis Kaye** as she knew both her parents (Donna and Wayne) had been very moved by it. Over the years Donna had spoken to Courtney about Dennis's humour, determination, and especially his resolve not to become absorbed in self-pity, even though it was very hard not to.

In spite of Courtney's tender age, ALS has had an impact on her more than once. Courtney's Grandfather died from ALS 20 years ago. Later, Courtney came to know Betty (Norman) during the last few months of her life. Courtney was only 7 when she attended the first Betty's Run (This One's For Betty). She also remembers climbing Mount Indefatigable (Robinson) to scatter Betty's ashes.

Courtney is a sensitive girl and very passionate about ALS. Courtney has agreed to share this poem with the ALS community ... for this we are grateful.



2004 Board Of Directors

Chair	Tim Stauff
Vice Chair	Cathy Martin
Treasurer	Shelley Engstrom
Director	Mark Stauff Daria Groch-Arnold Jan Desrosiers Anne Meininger Jim McLaughlin Karen Caughey Mike Klein

2004 Staff

Executive Director	Mary Hatcher
Coordinator, Provincial Office	Helen Desjardins
Manager, Resource Development	Wayne Steer
Coordinator, Equipment Program	Lyn Skipper
Coordinator, Southern Alberta Client Services	Jane Rivest
Southern Alberta Client Services (Part time contract position)	Janice Zoeteman
Manager, North Region	Patricia Ordynec
Administration & Volunteer Services, North Region	Phyllis Javorsky
Speech Language Path, North Region (Part time contract position)	Sue Decker

Treasurer's Report

Year Ended December 31, 2004

The year 2004 saw the financial picture of the Society making a significant positive shift from the previous year. Total revenues of \$727,774 increased by \$242,269 or almost 50% from the prior year, while overall expenses of \$635,221 increased by less than 14% or \$75,325.

In 2004, the Society experienced a significant increase in revenues generated through fundraising activities. This area has continued to remain a strong source of income over the years. Revenue from this critical activity has increased by 175% from last year, and through the hard work of our dedicated employees and volunteers, we expect that these revenues will continue to remain strong again next year and in the years ahead.

Budgets for the 2004 year were prepared with the involvement of those responsible for achieving the targets. Actual costs were less than initially budgeted in all expense areas due to the diligence and commitment to fiscal responsibility demonstrated by the staff members of the Society.

The overall financial position of the Society is strong and its operating base is solid. This sound fiscal condition will sustain the critical work of the organization in the years to come.

I would like to extend my thanks to all those who have helped me fulfill my role as Treasurer during the past year.

Shelley Engstrom, Treasurer, ALS Society of Alberta

AUDITORS' REPORT

To the Members of the

AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF ALBERTA

I have audited the balance sheet of the Amyotrophic Lateral Sclerosis Society of Alberta as at December 31, 2004 and the statements of operations and changes in net assets and cash flows for the year then ended. These financial statements are the responsibility of the Society's management. My responsibility is to express an opinion on these financial statements based on my audit.

Except as explained in the following paragraph, I conducted my audit in accordance with Canadian generally accepted auditing standards. Those standards require that I plan and perform an audit to obtain reasonable assurance whether the financial statements are free of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation.

In common with many charitable organizations, the Society derives revenues in the form of donations and fund raising events, the completeness of which are not susceptible to satisfactory audit verification. Accordingly, my verification of these revenues was limited to the amounts recorded in the records of the Society and I was unable to determine whether any adjustments might be necessary to revenues from donations and fund raising events.

In my opinion, except for the inability to verify the completeness of revenues referred to above, these financial statements present fairly, in all material respects, the financial position of the Society as at December 31, 2004 and the results of its operations and the changes in cash position for the year then ended in accordance with Canadian generally accepted accounting principles.

Calgary, Alberta

CHARTERED ACCOUNTANT

Joe Benaschak, CA

AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF ALBERTA

BALANCE SHEET

DECEMBER 31, 2004

ASSETS

	<i>2004</i>	<i>2003</i>
CURRENT:		
Cash and short-term investments	\$ 406,477	\$ 239,967
Accounts receivable	32,095	6,156
Prepaid expenses	3,187	29,381
	<hr/> 441,759	<hr/> 275,504
NET CAPITAL ASSETS (NOTE 3)	<hr/> 223,411	<hr/> 191,877
	<hr/> \$ 665,170	<hr/> \$ 467,381

LIABILITIES

CURRENT:		
Accounts payable	\$ 193,187	\$ 24,233
Accrued liabilities	1,000	1,000
Deferred revenue	1,000	25,000
	<hr/> 195,187	<hr/> 50,233
UNAMORTIZED CAPITAL CONTRIBUTIONS	<hr/> 216,317	<hr/> 186,501
DEFERRED CONTRIBUTIONS RELATED TO CAPITAL ASSETS	<hr/> 7,592	<hr/> 77,126

NET ASSETS

INVESTED IN CAPITAL ASSETS	7,094	5,376
UNRESTRICTED NET ASSETS	<hr/> 238,980	<hr/> 148,145
	<hr/> 246,074	<hr/> 153,521
	<hr/> \$ 665,170	<hr/> \$ 467,381

Approved by the Board:

AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF ALBERTA

**STATEMENT OF OPERATIONS
FOR THE YEAR ENDED DECEMBER 31**

	<u>2004</u>	<u>2003</u>
REVENUE:		
Donations	\$ 234,544	\$ 187,866
Betty's run for ALS	207,122	169,252
Fundraising	147,859	8,257
Walk to D'feet	169,949	137,453
Amortization of capital contributions	107,944	98,545
Third party fundraisers	3,235	4,557
Other	7,323	13,262
	<hr/> 877,976	<hr/> 619,192
EXPENSES:		
Client services	253,254	239,446
Research	150,202	133,687
Equipment	137,657	106,499
Amortization	109,586	100,809
Resource development	39,856	37,443
Education	29,097	29,412
Administration	28,913	24,668
Volunteer	15,770	14,490
Advocacy	11,665	2,309
Awareness	9,423	4,820
	<hr/> 785,423	<hr/> 693,583
EXCESS REVENUE (EXPENSES) FOR THE YEAR	<hr/> \$ 92,553	<hr/> \$ (74,391)

Shaping the Future

Over the past year, ALS AB has been strategically addressing the goals identified in the Organizational Assessment, positioning the Society for increasing effectiveness and fostering growth in ways that are consistent with the Mission Statement.

Increasingly the Society is taking ownership of programs and services that have traditionally been organized and supported by a third party.

Equipment: The Adaptive and Augmentative Communication Devices (AACD) program that serves southern and central Alberta has recently been brought in-house, providing more timely access to this equipment by those with ALS.

Resource Development: Expanded programs and services will only be possible if the Society can ensure a sustainable growth in revenue. There are some exciting initiatives being pursued in partnership with ALS Canada. Acres for ALS – Harvest of Hope and Hike for ALS are just 2 of the new events being considered for implementation in 2005 – 2006.

Communications & Community Relations: The ALS Society of Alberta sees value in recognizing those who help us in our mission and journey to support those living with ALS. Because of this commitment to honouring those who really stand out the ALS Society of Alberta is embarking on an awards program to recognize those individuals or teams who have excelled and demonstrated leadership in the areas of **Fundraising & Philanthropy, Advocacy, Awareness & Publicity, Support & Services, Education, Youth Initiatives** and **Volunteerism**. There is also an award category for one person to be honoured as a **Lifetime Member**.

This program has been developed to be congruent with our belief that positive reinforcement through recognition has a synergistic effect and energizes all parts of the Society. The positive effect of this program is to increase the overall effectiveness of the Society and the various stakeholders who support us; ultimately benefiting those living with ALS, their families and friends.

