

***AMYOTROPHIC LATERAL SCLEROSIS
SOCIETY OF ALBERTA AND N.W.T.***

ANNUAL REPORT

2001

MISSION STATEMENT

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.

www.alsab.ca

The ALS Society of Alberta

“ALS is clearly the most common cause of neurological death on an annual basis.”

– Dr. Michael Strong, research scientist at the Robarts Research Institute, London, Ontario

ALS, often called Lou Gehrig’s Disease, means Amyotrophic Lateral Sclerosis.
Sometimes it is called Motor Neuron Disease.

ALS can strike anyone. It can hit at anytime, regardless of age, sex or ethnic origin.
The usual age of onset is 55-65, but people under 20 have been diagnosed.

ALS is not a rare disease. Of every 100,000 people, between 6 and 7 will be diagnosed with ALS.

Between 1,500 and 2,000 Canadians currently live with ALS.

Two or three Canadians die each day of this devastating disease.

In at least 90% of cases, it strikes people with no family history of the disease.

ALS always results in death. 90% of people with ALS die within 5 years of diagnosis.

A person with ALS requires an average of \$40,000 in equipment alone.
Nursing care can cost several times that amount.

The cause is unknown. *There is no known cure* or treatment that prolongs life significantly – yet.

ALS Fast Facts

STATISTICS CANADA DEATH RATE DATA

		1994	1995	1996
ALS	Males	493	567	520
	Females	503	489	590
	TOTAL	996	1056	1110
CYSTIC FIBROSIS	Males	35	24	24
	Females	38	33	23
	TOTAL	73	57	47
MULTIPLE SCLEROSIS	Males	129	129	105
	Females	184	212	189
	TOTAL	313	341	294
AIDS	Males	1489	1637	1198
	Females	139	127	108
	TOTAL	1628	1764	1306

The Cornflower, A Symbol For ALS

The cornflower is the international symbol of ALS. It represents positive hope for the future.

The cornflower is an annual or biennial plant. It originated in Mediterranean Europe, and now flourishes across Canada.

The Cornflower symbolizes courage. Despite its fragile appearance, it can withstand both frost and drought. Its peaceful, strong blue color 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.

A Message from our Honorary Chairman

The ALS Society of Alberta / NWT is dedicated to its Mission of "making everyday the best possible day for people with ALS." Through the work of the Society, people with ALS have access to a high and constantly improving level of services, regardless of where in the province they live. It is an honour to be their Honorary Chair.

I applaud the many and varied efforts that go into raising the dollars and the awareness needed to make a difference. We are better today than we were yesterday, and I am very confident we will be better tomorrow than we are today. Congratulations on all you have accomplished and all the best in 2002.

Jim Gray, O.C.

Founder and Former Chairman, Canadian Hunter Exploration Ltd.

Honorary Chairman, ALS Society of Alberta

A Message to our Volunteers

Simply, the ALS Society of Alberta could not exist without the 335 amazing volunteers that give us their time and expertise. Through your efforts, awareness is spread and funds are raised. This allows us to provide services for the present and hope for the future. Whether you come into the office to help the staff, sit on committees that drive our ongoing events like the Betty's Run or begin new events, like the Walk's to D'Feet ALS, or provide leadership and vision as board members, you unquestionably help to make everyday the best possible day for people with ALS.

Thank you, Volunteers – Together, we do make a difference.

BOARD OF DIRECTORS

Jim McLaughlin	President
Tim Stauff	Vice President
Terra Parkinson	Secretary
Mike Wright	Treasurer
Jim Bowling	Director
Doris Caouette	Director

STAFF

Mary Hatcher	Executive Director
Jane Rivest	Client Services Co-ord. (South)
Patricia Ordynec	Support and Education Co-ord. (North)
Anne Chapman Heinemeyer	Equipment Program Co-ord.
T.O. Whenham	Manager of Resource Development
Julie Kerr	Client Care Assistant (Calgary)
Lyn Skipper	Equipment Program Assistant
Helen Desjardins	Secretary (Prov. Office)
Karen Andrus	Admin. Assistant (Edmonton)

PRESIDENT'S REPORT

Commemorating the International Year of the Volunteer

The past year has been another exceptional year for the ALS Society of Alberta/NWT. As an organization we have continued to focus all our efforts on making every day the best day possible for people with ALS and their families. This could not be accomplished without the tireless efforts of wonderful staff and dedicated volunteers.

Mary Hatcher has been the Executive Director for the past four years and continues to lead the organization with compassion and clarity of vision that has helped us grow and mature. At the same time, Mary is surrounded by a wonderful group of talented and hard working staff who bring a special blend of skills and talents to their work with people we serve. The Society is extremely fortunate to have the current complement of staff in Calgary and Edmonton and owes each one of these individuals our deepest gratitude.

On behalf of the Board of Directors I would also like to extend sincere thanks to all the people who work as volunteers and have done a remarkable job supporting the efforts of the Society. A very special thanks goes out to all the people living with ALS who have given their time and energy to help others. You are the beacon we all follow. Thank you to all the volunteers who have cared for people with ALS and their families. Thank you to everyone responsible for the incredibly successful Betty's Run for ALS. Thank you to the volunteers who have made Evelyn's Tee Off for ALS an annual success and to the people in Hanna who raised money and awareness in the Friends of Garth Hanlon Golf Tournament for ALS Awareness. Thank you to everyone in Edmonton and Medicine Hat who organized and participated in the Walk to D'feet ALS. Thank you to the dedicated folks in Edmonton who have worked so hard to maintain a successful Chapter. Thank you to all the volunteers who help in so many different ways.

A special thanks to all the funders, sponsors and donors who have made financial contributions towards helping us provide care and find a cure. Your support is greatly appreciated and helps us help others.

The ALS Society of Alberta/NWT is truly a community of people who live out the mission "to make every day the best day possible for people with ALS." Together we will triumph over this devastating disease.

Jim McLaughlin, President

EXECUTIVE DIRECTOR'S REPORT

2001 was a year of strong growth and positive change for the ALS Society of Alberta. "Making everyday the best possible day for those with ALS" remains our focus in everything we do, and we are doing it better than ever before.

In Northern Alberta, we welcomed Patricia Ordynec as Support and Education Coordinator, and Karen Andrus to provide support to the office and to volunteers. We also moved to a bright, spacious new office, which dramatically increases our ability to provide services in Northern Alberta.

In Southern Alberta, Julie Kerr joined the Client Care team, providing support to people with ALS in Calgary.

The Provincial team also grew. T.O. Whenham joined us as Manager of Resource Development to oversee and grow the fundraising and awareness programs. Lyn Skipper joined us to assist in managing the Equipment Program.

The ALS Alberta Equipment program continues to grow and is serving our ALS Clients better than ever before.

There has been a huge growth all across the province in the demand for in-services and workshops requested by community groups and health care providers. In 2001 Jane and Patricia combined to provide more than 25 sessions, reaching more than 500 people. As well, staff members are increasingly being asked to present at regional and national workshops and conferences.

ALS Alberta continues to be heavily involved with the Alberta Partnership for Health and is working ever more closely with Hospice Calgary and Pilgrim's Hospice in Edmonton as well as with the Palliative Care Association of Alberta. Because the ALS Society serves a small population with very high needs it is greatly to our benefit to address mutual issues and concerns with other health charities and consumer groups.

Mary Hatcher
Executive Director

Treasurer's Report - Year Ended December 31, 2001

The year 2001 saw total revenues increase to \$605,105 up by \$209,255 over the previous year. This coupled with restraint on expenses enabled the Society to achieve a modest surplus of \$16,574 compared with a deficit of \$66,440 the year before.

Once again the budgets were prepared with the involvement of those responsible for achieving the targets set in those budgets which augurs well for reaching the budgeted revenue and expense levels in 2002. For the first time, departmental expense statements are now prepared on a monthly basis, showing both the monthly and year to date figures for actual and budget amounts. This improves our ability to pinpoint and correct any variations from the budgeted level of expenditures should these occur.

The Society still faces, quite likely will always face, the need for a greater level of funding, but I believe that steps taken in 2001 have set us on the right path to achieve even greater results in the future.

My thanks to all those who have helped me in the preparation of budgets and improved financial reporting.

Mike Wright
Treasurer

AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF ALBERTA

STATEMENT OF FINANCIAL POSITION**DECEMBER 31**

ASSETS

	<u>2001</u>	<u>2000</u>
CURRENT:		
Cash and short-term investments	\$ 367,957	\$ 245,762
Accounts receivable	6,168	11,596
Prepaid expenses	18,187	15,559
	<hr/> 392,312	<hr/> 272,917
NET CAPITAL ASSETS (NOTE 3)	<hr/> 203,774	<hr/> 177,426
	<hr/> \$596,086	<hr/> \$ 450,343

LIABILITIES

CURRENT:		
Accounts payable and accrued liabilities	\$ 113,196	\$ 29,711
Deferred revenue	16,439	37,696
Current portion of long term debt (Note 4)	10,330	10,330
	<hr/> 139,965	<hr/> 77,737
UNAMORTIZED CAPITAL CONTRIBUTIONS	<hr/> 223,036	<hr/> 164,082
DEFERRED CONTRIBUTIONS RELATED TO CAPITAL ASSETS	<hr/> 50,816	<hr/> 42,829
NET ASSETS, UNRESTRICTED	<hr/> 182,269	<hr/> 165,695
	<hr/> \$ 596,086	<hr/> \$ 450,343

AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF ALBERTA

STATEMENT OF OPERATIONS AND NET ASSETS

FOR THE YEAR ENDED DECEMBER 31

	<u>2001</u>	<u>2000</u>
REVENUES:		
Fundraising	\$ 280,690	\$ 121,724
Bequest and anonymous donations	150,000	150,000
Amortization of capital contributions	68,125	42,709
General donations	63,678	48,013
Memoriams	32,411	25,606
Interest and other income	10,201	7,798
	605,105	395,850
EXPENSES:		
Wages and related costs	228,777	185,419
Research	103,825	75,759
Amortization	101,767	84,278
Rent	36,985	22,210
Client equipment expense	28,132	27,451
Office supplies and expense	26,957	17,463
Travel	19,158	12,422
Telephone and fax	13,339	8,931
Awareness and education	11,254	3,786
Professional fees	8,728	18,867
Insurance	4,626	3,246
Memberships and dues	3,462	930
Miscellaneous	1,521	1,528
	588,531	462,290
EXCESS REVENUES (EXPENSES) FOR THE YEAR	16,574	(66,440)
NET ASSETS, BEGINNING OF YEAR	165,695	232,135
NET ASSETS, END OF YEAR	\$ 182,269	\$ 165,695

RESOURCE DEVELOPMENT REPORT

Our participation in the prestigious Fundraising and Resource Development Project sponsored by the Kahanoff Foundation resulted in a number of very positive developments for the Society. Most important was the hiring of a full time Manager of Resource development for the first time. This has allowed us to develop a solid and achievable Resource Development Plan that will ensure our long term viability and growth. Existing programs are being strengthened, and new programs are emerging that will make us stronger into the future.

In September 2001 the Walk to D'Feet ALS was born. This national signature event raises huge amounts of awareness and significant funds for client services and research. 8 Walks were planned, and the goal was to raise \$250,000. In the end, more than \$556,000 was raised. Incredibly, \$105,000 was raised in Edmonton and Medicine Hat. In 2002, 24 Walks will be held nationwide, including five in Alberta. These new events have quickly become an important piece of our fundraising program.

Our capacity to provide advocacy and increased awareness at the government level is important, and we are working to increase our effectiveness. In 2001, we responded to the Mazankowski report, reminding the Alberta government that quality end of life care concerns must be addressed as well acute care and wellness. As well considerable effort has gone into developing our very own web site (www.alsab.ca) and we look forward to launching it early in 2002.

T.O. Whenham
Manager, Resource Development

ALS INFORMATION

What is ALS?

ALS is a rapidly progressive neuromuscular disease. It attacks the nerves that the body would normally use to send messages from the brain to the muscle, resulting in weakness and wasting. Eventually, the individual with ALS is left completely paralysed, with loss of speech, swallowing and breathing. The mind remains completely alert and lucid. A lively, unimpaired mind is trapped in an immobilized body. The average life expectancy at diagnosis is 2.5 years.

What causes ALS?

In the majority of cases, the cause is unknown. Research is being conducted in areas relating to genetic predispositions, viral or infectious agents, environmental toxins and immunological changes. Some of this research is happening right here in Alberta.

Is there a cure?

Simply, no. There is no treatment that prolongs life significantly. Some drugs now available and others being developed will offer new treatment options. Research is investigating ways to reverse the disease. There may be a cure, eventually.

What are the effects of ALS?

As the disease progresses, individuals become completely dependent and increasingly unable to communicate their needs. Institutionalization is rare; care is almost always provided by family members. Often, family members must quit their jobs to provide this care. This adds enormous financial strain to the already severe emotional stress on families coping with the impending loss of a loved one.

What does the ALS Society of Alberta do?

Information, Referral and Home Visits: We provide individuals with ALS and their families information about ALS, and the services that are available. We provide further help in navigating the health care system and in accessing equipment and services in a timely fashion. Staff members conduct home visits to offer support, and stay in touch by phone and E-mail.

Equipment and Assistive Technology: Mobility devices, such as power wheel chairs and scooters, and communication equipment, such as laptop computers and electronic speech devices, give freedom of movement to the paralysed and a voice to the silent. These items, as well as hospital beds and lifts are all equipment that a person with ALS will need during the course of the disease. ALS is a rapidly progressive disease, and individuals cannot afford to wait for the equipment they need. The ALS Society provides equipment, works with families and insurance companies to fund the equipment and makes up any funding shortfall. The society maintains a pool of equipment so that the right piece of equipment may be available immediately.

Support Groups: The ALS Society believes that by sharing the frustrations, fears and inspirations of individuals and family members, barriers of isolation and loneliness can be broken. Bringing individuals with ALS together provides an opportunity for each to help and support the other.

Awareness and Education: To beat this disease we must make people aware. The Society does this by publishing books, producing videos, maintaining a website and promoting the ALS cause at special events. The society also works with medical professionals and caregivers to make sure they know about the disease and how to deal with it.

OUR VISION

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

OUR VALUES

RESPECT: We treat everyone as people first and foremost, and respect their rights and responsibilities.

CARING: We show compassion. We help those in need and avoid harming others.

SERVICE: We are involved in efforts to serve the needs of people affected by ALS, without the motive of personal gain. We provide services in a fair and equitable manner.

ACCOUNTABILITY: We are responsible for our decisions and actions made on behalf of the society. We demonstrate due diligence in fulfilling our commitments to our members, their families and friends, volunteers, funders and all others who provide support to our members. We are committed to the continuous improvement of our Society for the betterment of our members.

PASSION: We demonstrate a strong, emotional enthusiasm in our endeavours to make a positive difference in the lives of people affected by ALS. We communicate this enthusiasm to others in an attempt to encourage others to share in our vision.

QUALITY OF LIFE: We endeavour to ensure that all people in Alberta with ALS are afforded the highest level of support and services.