

AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF ALBERTA AND NWT



Annual Report 2003

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.

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.

Vision

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

The ALS Society of Alberta/NWT is a community of people who live out the mission “to make every day the best day possible for people with ALS and their families.” This vision is accomplished through providing support, the provision of care and equipment, and advocacy toward a cure. All of which requires countless hours of volunteer time, the generosity of donors, and the courage of those affected by ALS. For this, the society is eternally grateful.

The society and its volunteers have been recognized nationally for its efforts, and it is truly amazing to see the difference we can make in people’s lives. It is “making a difference” that keeps us focused, and determined to continue.

Tim Stauff
Chair ALS Society of Alberta

Values

These words summarize what the ALS Society of Alberta is committed too. These values are an integral part of our mission statement.

RESPECT
CARING
QUALITY OF LIFE



PASSION
SERVICE
ACCOUNTABILITY

2003 Highlights

CEP Automotive Golf Tournament

In September, CEP Automotive in Lethbridge raised over \$16,000 for the ALS Society of Alberta.

Everyone remembered Dieter Abraham, the co-owner of CEP Automotive, who had passed away from ALS in July. The tournament will be renamed next year in memory of Dieter.



National Conference of Hospice Palliative Care

In June, Janice Hagel and Jane Rivest presented: *Palliative Care and ALS. What have we learned so far?* at the National Conference of Hospice Palliative Care in Quebec City.



The presentation included interviews conducted with people living with ALS, health care professionals, care providers and family members. In addition, an extensive literature review was completed and the presentation wrapped up with a communication practice, giving the audience communication strategies when working with non-speaking individuals.

Edmonton ALS Remembrance Service

This event was organized by the ALS Team (ALS AB and the ALS Clinic) in Edmonton and held at Pilgrim's Hospice. For people who lost loved ones to ALS it was an opportunity to reflect, remember and celebrate the life with others who had travelled the same path.



Walk to D'Feet ALS



This year walks were held throughout Alberta including Edmonton, Lethbridge, Medicine Hat and several rural locations. They were a success and we anxiously await the walks for 2004.

North Volunteers grew in numbers

In the North Region a total of 90 volunteers gave 1668 hours to the ALS Society in 2003, an increase from 40 volunteers and 1476 hours in 2002.



Charitee Golf Tournament

On July 14 the Corporate Calgary Charity Society hosted their first annual Charitee Golf Tournament at Pinebrook Golf and Country Club. All funds raised this year went to the ALS Society of Alberta.

With 88 enthusiastic golfers in attendance, \$50,000 was raised for the purchase of much-needed equipment for ALS patients.



ALS Team Roping Event



On August 22, the Eagle Valley Roping Association in Sundre held their third annual team roping event and raised over \$2000 for the ALS Society of Alberta. The majority of participating cows used were donated, helping to make this event a huge success. In addition, a large amount of prize money was donated back after having been won, to benefit ALS Alberta.

Torrington Old Time Music and Dance Jamboree

Torrington, Alberta was host to the Old Tyme Music & Dance Jamboree between August 14 - 17, 2003. Large crowds came out to enjoy the hot summer weather and wonderful music, with proceeds coming to the ALS Society of Alberta.



Calgary Outlaws/ Edmonton Trappers Baseball game



On June 14 and 18 the ALS Society of Alberta partnered with the Calgary Outlaws and Edmonton Trappers to host a birthday celebration for Lou Gehrig. Baseball fans were greeted at the gate with Lou Gehrig pins and were encouraged to celebrate the life and achievements of this great baseball legend, who would have been 100 years old.

Lou Gehrig shirts were thrown into the crowd of over 1,800, while Gehrig's outstanding baseball record statistics were read to the stadium.

Milestones

Betty's Run for ALS

In August 1996, Betty Norman, a vivacious, fun-loving, and caring lady was diagnosed with ALS. Betty, along with family and friends were frustrated by the lack of ALS awareness and the small amount of research being done at the time. In response to these issues, the first walk/run in Betty's honour was held in Calgary in June 1997, two weeks before Betty passed away.

In June 2003, Betty's Run for ALS achieved an extraordinary milestone by raising an accumulative \$1,000,000 since the first one seven years ago. To date \$500,000 has been sent to ALS Canada for research and to find a cure. The remaining \$500,000 has stayed in Alberta to help provide appropriate equipment and support for people currently living with ALS.

Betty's Run for ALS has been the leading force behind the National Public Service Announcements for ALS, thanks in great part to the participation of Wendy Crewson in 1999 and 2003.



What drives us to do this year after year? Each and every member of the committee knows a friend or family member with ALS.

ALS Canada Mary Pollock Walk to D'Feet Award

The Yates family of Edmonton were awarded the first Mary Pollock Walk to D'Feet ALS Volunteer Award. Chris and Teddy Yates, along with daughter Heather, have been central to the success of the Walk to D'Feet ALS in Edmonton and beyond.



The Yates family have been instrumental in inspiring families affected by ALS across Alberta to develop their own Walk to D'Feet ALS. These walks have involved more than 1,000 walkers and nearly \$200,000 has been raised for ALS research and services.

The Yates's family retired at the end of 2003. They will be missed.

From left: Heather, Teddy and Chris Yates with, Stu and John Pollock

Treasurer's Report

Year Ended December 31, 2003

The year 2003 saw the financial picture of the Society shifting slightly from the previous year. Although total revenues of \$619,192 decreased by 13.8 per cent from the prior year, overall expenses of \$693,583 remained approximately the same as 2002 (1.3 per cent increase).

Although the Society experienced an overall decline in revenues, funds generated through fundraising activities and general donations have continued to remain a strong source of income over the years. Revenues from these two critical areas have grown by approximately 142 per cent over a four-year period, and through the hard work of our dedicated employees and volunteers, we expect that these revenues will increase once again next year and in the years ahead.

Budgets for the 2003 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.

Although the Society ended the year with an overall operating deficit of \$74,391, the overall financial position of the Society remains positive and its operating base is solid.

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*



AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF ALBERTA

STATEMENT OF FINANCIAL POSITION

DECEMBER 31

ASSETS

	<u>2003</u>	<u>2002</u>
CURRENT:		
Cash and short-term investments	\$ 239,967	\$ 312,086
Accounts receivable	6,156	13,472
Prepaid expenses	29,381	24,738
	275,504	350,296
NET CAPITAL ASSETS (NOTE 3)	191,877	186,427
	\$ 467,381	\$ 536,723

LIABILITIES AND NET ASSETS

CURRENT:		
Accounts payable	\$ 24,233	\$ 38,470
Accrued liabilities	1,000	3,000
Deferred revenue	25,000	22,439
	50,233	63,909
UNAMORTIZED CAPITAL CONTRIBUTIONS	186,501	185,766
DEFERRED CONTRIBUTIONS RELATED TO CAPITAL ASSETS	77,126	59,136
NET ASSETS, UNRESTRICTED	153,521	227,912
	\$ 467,381	\$ 536,723

Board approved

June 1, 2004

AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF ALBERTA

STATEMENT OF OPERATIONS AND NET ASSETS

FOR THE YEAR ENDED DECEMBER 31

	<u>2003</u>	<u>2002</u>
REVENUES:		
Fundraising	\$ 318,254	\$ 444,649
Amortization of capital contributions	98,545	78,541
General donations	92,366	104,320
Bequest and anonymous donations	50,000	-
Memorial donations	47,480	53,381
Interest and other income	12,547	10,676
Grant – Calgary Foundation	-	27,002
	619,192	718,569
EXPENSES:		
Wages and related costs	282,159	259,753
Research	133,686	143,988
Amortization	100,809	70,161
Rent	52,091	41,002
Client equipment expense	30,366	46,932
Office supplies and expense	23,508	27,830
Travel	17,681	22,808
Awareness and education	16,756	15,574
Telephone and fax	14,973	14,518
Professional fees	10,032	7,847
Insurance	3,458	5,567
Memberships and dues	3,204	3,496
Calgary Foundation – community services project	-	23,155
Miscellaneous	4,860	1,838
	693,583	684,469
EXCESS REVENUES (EXPENSES) FOR THE YEAR	(74,391)	34,100
NET ASSETS, BEGINNING OF YEAR	227,912	193,812
NET ASSETS, END OF YEAR	\$ 153,521	\$ 227,912

Shaping the Future

In 2003 ALS AB began two very important initiatives that will provide shape and focus to the Society over the next several years.

The first is an Organizational Assessment. This initiative, conducted through the Calgary Center for Non-Profit Management, will provide a broad appraisal of the Society's current state of health and identify strategies for improving overall performance. Areas under review include governance, fund development, financial management, human resource/volunteer management and information & communication technologies. We look forward to having the final report in 2004 and to using it as the basis for revising the ALS AB Strategic Plan in 2004.

The second is planning for a day at the Alberta Legislature. In the spring of 2004 ALS AB will issue invitations to all Members of the Legislative Assembly to meet with representatives from ALS AB. Each MLA will be given information about ALS, the role of the Society and a carefully crafted message letting our elected officials know of the needs of Albertans with ALS and what the government can do to help. A group of dynamic and dedicated Edmonton volunteers is planning this event with support from staff and Advocacy Board members. It is being modelled on the very successful "Hill Days" that ALS Canada has twice done in Ottawa.

Mary Hatcher & Tim Stauff
Executive Director Chair





“When I was first diagnosed with ALS, I had no idea what it even meant. I just thought ‘give me a vitamin and make me better’. Then the doctor explained: “In about twelve months you’ll be using a wheelchair. You have a life expectancy of about three years.”

It was like being kicked in the stomach. Quite literally I had the wind knocked out of me. Just moments before I had been on top of the world, with so many dreams waiting to be fulfilled. I was newly married and had a position overseas in the military.

I was extremely angry. I tried blaming everyone. But no matter how angry I got, the disease still progressed. It became apparent very soon that I couldn’t continue active service. Within a few months my wife Linda and I were back in Canada and about two years after that I retired. It wasn’t quite what I’d expected out of life. I felt out of control and I wished I could have died.

Then one day I realized – even though there were many things I could do absolutely nothing about, there was one thing that I could control. That was my attitude. There was more to life than worrying about my disease. I was married to the woman I loved, and we wanted a family together. And I was still able to participate in life! That decision meant that I would require a great deal of support in the form of equipment and assistive devices, assistance navigating through the health care system in search of services, and education of this disease. That support came to me in the form of the ALS Society.

That was over ten years ago. Today, I am in a wheel chair; I tire easily and need help with everyday things that I used to take for granted, like eating and dressing. But I’ve chosen to focus on what I can do as opposed to what I can’t. I’ve outlived the three-year life expectancy prognosis. I wake up every morning and I am Michael first! I just happen to have ALS. Linda is always there for me and we have a beautiful son, J.D. and a newborn daughter, Carly.

Sure, it’s difficult to think about the future. It does make me sad. But there is so much to focus on day-to-day. I do a lot of work for the ALS Society. I want to get out there and get the message across about ALS. It is a devastating disease that knows no racial, gender or age barriers. It changes everything in your life and in the lives of those around you, from working to talking and even breathing. But life doesn’t end at diagnosis.

I’m hopeful that with more research and support we will find better treatments and a cure. I’m hopeful that people will care enough to listen and to help. I never give up hope. Many experimental drugs are being tested right now and I have a lot to live for. For myself and for my family, hope is what keeps us going. Thank you for taking the time to read my story.”

Yours truly,

Michael Speelman C.D.