



**Amyotrophic Lateral Sclerosis
Society of Alberta**

Annual Report 2013

OUR VISION

To make each day the best possible day for people living with and affected by ALS.

We achieve our vision by providing support, facilitating the provision of care, promoting awareness, helping find a cure and advocating for change.



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MESSAGE FROM OUR HONOURARY CHAIR

JAMES K. GRAY



Dear Friends of the ALS Society of Alberta,

It has been my great honour to have been connected to you for the past 16 years as Honourary Chair of the ALS Society. My engagement with the Society began in 1996 when one of my colleagues, Betty Norman, was diagnosed with ALS. Betty, along with her friends and family, wanted to do something that would make a difference to lives so painfully affected by this cruel disease. The birth of Betty's Run occurred shortly thereafter but, sadly, Betty passed on just after the first run. Her vision for the Run

would continue to allow the Society to provide supports to ALS patients to enable them to live the remainder of their lives with grace and dignity.

All these years later, my enthusiasm for the work of the Society has not diminished. I'm as pleased today with my connection as I was back in 1998. I have seen all manner of things occur which confirms to me that the ALS Society of Alberta is utterly necessary in our community. The Walks, the Tournaments, the Runs and the many other fundraising events are all examples of important efforts by hundreds of volunteers who work selflessly to ensure their success and, by doing so, allow the Society to support ALS patients and their families through their time of great need.

I want to thank you all for your interest in this wonderful Society and I look forward to your continued support.

James K. Gray, O.C., A.O.E.

MESSAGE FROM OUR HONOURARY PATRON

HIS HONOUR, COL. (RET'D), THE HONOURABLE DONALD S. ETHELL LIEUTENANT GOVERNOR OF ALBERTA

As Her Majesty the Queen's representative, it's my pleasure to extend sincere congratulations to the ALS Society of Alberta on a very successful year.

Being diagnosed with a condition like ALS isn't something anyone ever wants to experience. It's a cruel and unrelenting disease and I hope and pray that one day soon it will be cured and relegated to the history books. Until that day comes, people and families living with the condition will continue to turn to the ALS Society of Alberta for understanding, help and support. I'm well aware that the success the Society has achieved over the years, and the difference its members have made in the lives of so many people, is the result of a remarkable amount of careful thought, effort and planning. The Society's staff, volunteers and supporters only want the best for Albertans living with ALS and their commitment to that goal shines through in everything they do.

I wish the Society continued success in the year to come and I extend my best wishes to those among us who are battling ALS. My thoughts and prayers are with you always.

*Donald S. Ethell, OC, OMM, AOE, MSC, CD, LLD
Lieutenant Governor of Alberta*



MESSAGE FROM OUR CHAIR & EXECUTIVE DIRECTOR

TARA PENTNEY & KAREN CAUGHEY

Tara Pentney



The year 2013 ended with the Society enjoying a strong organizational and financial position. We completed the 2008-2013 five year strategic plan and confirmed that the priorities of our next five year strategic direction will focus on our Programs and Services, Fund Development and Awareness.

Karen Caughey



We supported the highest number of people and their families in the history of the Society. We were able to fulfill our mission by responding to 100% of the requests for equipment, completed more than 1,600 home visits and raising more than \$421,000 for research.

The Society participated in the development of a formal agreement with the ALS Societies across Canada to strengthen the network to ensure all Canadians affected by ALS receive the support they need and to affirm the importance of funding of critical research into treatments and a cure. A team from Alberta participated in Hill Day in Ottawa with our 10 partners to advocate for an increase of compassionate care benefits for our families and the reinstatement to funding for ALS research.

We value our partnership with the ALS Clinics in Alberta and continue to work collectively to support our families. There has been a planned focus on the growth of our Equipment Loan Program. We secured new space in Edmonton that will house our combined office space and equipment storage for the North Region.

Our families are the essence of the Society. Your strength and courage inspires us to ensure our focus remains on our mission. We are privileged to be a part of your lives during this intense time and value the time you give to move the cause forward.

To say thank you isn't enough to our wonderful, dedicated volunteers and staff team across Alberta. We are able to fulfill our mission to make each day the best possible day for people living with and affected by ALS because of the strength that comes from working together.

AMYOTROPHIC LATERAL SCLEROSIS

WHAT IS ALS?

Amyotrophic Lateral Sclerosis (ALS) is also known as Lou Gehrig's disease. It is a rapidly progressive, always fatal neuromuscular disease. It is characterized by the degeneration of a select group of nerve and cell pathways (motor neurons) in the brain and spinal cord which leads to progressive paralysis of the muscles.

ALS can strike anyone. It is not contagious, does not discriminate, and can strike at any age. ALS most often occurs between the ages of 40 and 70, but it can occur in older and younger adults, and sometimes in teenagers. ALS is usually fatal within two to five years of diagnosis. There is a hereditary pattern in approximately 10% of cases. There is currently no known cause or cure...yet.

SERVICES

WHAT WE PROVIDE

The ALS Society of Alberta provides services and support to people living with and affected by ALS across the province.

We do this by:

- Providing Support
- Facilitating the provision of care
- Promoting awareness
- Helping to find a cure
- Advocating for change



PILLARS OF THE SOCIETY

STRATEGIC AND OPERATIONAL PLANS

The ALS Society of Alberta bases its strategic and operational plans upon the following seven pillars:

- Programs & Services
- Research
- Resource Development
- Public Awareness
- Advocacy
- Governance
- Management



PILLAR ONE

PROGRAMS & SERVICES

Providing services and support for clients, families, caregivers and health care providers. This includes: Information and Education, Communication and Assistive Equipment, Support Groups, Care Coordination, Referrals, Home Visits and other services as identified.



As one of our key strategic priorities, providing support and equipment for people living with ALS in Alberta is the foundation of the mission of the Society.

In 2013, the Society supported 320 people and their families affected by ALS. We made more than 1,600 home visits, loaned more than 1,400 pieces of equipment and held over 87 support groups across Alberta.

We are proud to report that we supported 16 families affected by ALS through our Support for Champions Children's Program. We also supported Errol Bindon from Calgary to attend the Youth Retreat hosted by ALS Saskatchewan.

Here is the story of one of our clients. Wayne Erickson was diagnosed with ALS in December 2012. Wayne, along with the support of his wife Norma, has managed through his journey with ALS with strength and determination. Wayne retired in 2005 from the food industry as a produce merchandiser. This was a time that Wayne could pursue his love of photographing wildlife. His particular love of owls has become his signature. He proudly displayed his photos on his T-shirt as he participated in the WALK for ALS. Last year was bitter-sweet as it was one of the last opportunities that Wayne could pursue his photography. ALS has taken this away.

With the support of our Programs and Services, Wayne has been able to continue to make each day the best possible day living with ALS. Equipment such as a power wheel chair, porch lift, ramps and easy lift chair have made it possible for Wayne to live more comfortably at home and continue to participate in most of the things he loves to do.

Wayne and Norma were among the 1,100 participants at the Edmonton WALK for ALS last year and unselfishly gave of their precious time to raise funds and create awareness for ALS. "It is a privilege to work with Wayne and Norma as they give so much to the ALS Community," Brandee Fossen, Manager Edmonton.



Photo taken by Wayne that is displayed on his team's WALK for ALS T-shirts

PILLAR TWO RESEARCH



*Dr. David Taylor, Dr. Chris White,
ALS Society Staff and Volunteers*

Supporting and contributing funds towards research for the treatment and cure of ALS.

The ALS Society of Alberta is the one of the largest contributors to national research across Canada. In 2013, the ALS Society of Alberta raised over \$420,000 through our Signature Events, the WALK for ALS, Betty's Run for ALS and gifts to send to ALS Canada for national research.

We communicate important updates on current research initiatives to our families and clients through our website, newsletters and special events.

Funds raised for research help to support initiatives such as, national research grants, the development of young research investigators, the Canadian Neuromuscular Disease Registry (CNDR) and critical research projects into treatment therapies and a cure for ALS.

The ALS Society works closely with the Neuromuscular Clinic in Calgary and the University of Alberta ALS Clinic in Edmonton. In 2013, we have continued to provide LVR (Lung Volume Recruitment) kits to the clinics. The partnership that the Society holds with the ALS Clinics is an extremely important and significant relationship that allows for greater support for people living with ALS.

PILLAR THREE

RESOURCE DEVELOPMENT

Optimizing all resource generation opportunities and partnerships to ensure the Society's financial sustainability.

Biemans Family and Singer Adam Gregory



Funding for the ALS Society of Alberta's services and programs comes the WALKS for ALS, Betty's Run for ALS, the ALS Charitee Golf Tournament, numerous Third Party Fundraisers, corporate sponsors, foundations, memorial and general donations, gaming, planned giving, bequests and an anonymous donor.

In 2013, Betty's Run for ALS and the WALKs for ALS raised over \$1,089,000. An exciting experience was had at the ALS Charitee Golf Tournament when Royal Oak Audi gave away a 2013 Audi Q5 SUV to Hole-in-One Winner Paul Smith!

Our anonymous donor supported the ALS Society's Equipment Loan program to ensure our clients have access to much needed equipment. We received a significant bequest from the Dutton estate to be used for the Society's equipment program.

The ALS Society is a member of the National Partners Fund Development Committee which works to strengthen fundraising across Canada. In 2013, we also developed and began the implementation of our three year Resource Development Plan.

The ALS Society was chosen as one of three charities to participate and benefit from the Calgary Motor Dealers Association (CMDA) Vehicles and Violins Gala. We received over \$125,000 from the event!

More than 30 third party fundraisers were held across the province. One of those events is Quonset Days, which was started by Janet Biemans and her family as a tribute to her loving husband Peter, who passed away in August 2009 after a hard fought battle with ALS. As a family, they wanted to raise money and awareness for the ALS Society of Alberta while celebrating the life of a truly wonderful man. The first Quonset Days in 2010 was organized in only a little over a month and each year they get bigger and better! In 2013, Quonset Days raised over \$30,000! The fun includes a silent & live auction, kick off party, live bands, beer gardens and free camping all held on their family farms. It truly is the "Greatest Outdoor Party on Dirt"!!

All of these amazing sources help us to fund our services and programs to help make each day the best possible day for people living with and affected by ALS. We are truly grateful for everyone who helps us to reach this goal.

PILLAR FOUR PUBLIC AWARENESS



Increasing public awareness about ALS and the ALS Society of Alberta through effective communication and education.

The ALS Society raises awareness among the medical community and the Alberta public about the ALS disease and the services available through the Society and other organizations through workshops, seminars, and special forums such as the website. In 2013 we developed and implemented our three year communications plan. This plan will guide the messaging and dissemination for the coming years.

The ALS Society is contacted for various projects that will create public awareness of ALS. Disabled and Dangerous is one of those projects: In 2008, Barry Varga was diagnosed with ALS. With the support of his family and friends, and his amazing outlook on life, Barry has continued to live each day with determination, passion and humour. Barry decided he had to do something that would bring some laughter and humour at such a dark time, and also raise awareness about ALS.

Disabled and Dangerous is the outcome of Barry's hilarious perspective coupled with his ambition to bring people together to make a comedy project to raise awareness and funds for ALS. The characters in the film are based on Barry's close friends, which he met at an ALS support group. Unfortunately, his friends have since passed away, but they will live on through the characters in the film.

In December 2011, Barry and brothers, Levi and Kyle McCachen worked with dozens of volunteers (family, ALS community, and friends) who wanted to participate in Barry's dream film. After a whirlwind of preparation and community enthusiasm, this broad comedy classic buddy movie was born.

The trailer was released online on December 9, 2013 and received more than 30,000 hits. On December 19, 2013, Disabled and Dangerous was released on YouTube for the world to enjoy. There have been 5,379 hits on YouTube to-date. The media coverage has been tremendous, with CTV, Global TV, the Calgary Herald and CBC Radio all doing live interviews.

The Vargas and McCachens together brought life to Barry's vision and had the courage to share their film despite the sensitivity of ALS. For this amazing work, these two families were nominated by the Society for the ALS Canada Tony Proudfoot Exceptional Public Awareness Program Award. The families will receive this award in 2014.

PILLAR FIVE

ADVOCACY

Advocating for change on behalf of and along side people living with and affected by ALS to ensure that each day is the best possible for them.

*Hon. Laurie Hawn,
Karen Caughey,
Dr. Wendy Johnston,
Monica and Roger
Brightwell*



Efforts to raise the awareness and consciousness of government and community support systems are a critical component of the role of the Society. As a result, the Society has also taken an active role in urging the federal and provincial governments to address such issues as increased funding for research, more timely delivery of services, additional comprehensive coverage for equipment and care, and more comprehensive palliative care.

One such initiative occurred on November 19, 2013, when a delegation of people living with ALS, along with researchers and representatives from ALS Societies across Canada met with MPs and Ministers on Parliament Hill on what is known as “Hill Day”. The Society was represented by Monica and Roger Brightwell, and Executive Director, Karen Caughey. Dr. Wendy Johnston represented the University of Alberta ALS Clinic.

ALS Society representatives are seeking the support of Parliamentarians and officials on two pressing priorities: first, to increase the Compassionate Care Benefit period from 6 to 35 weeks for families affected by ALS. Second, to establish a matching contribution of \$1.5 million per year from the federal government to the ALS Canada Research Program through a Rare Disorder Strategy. The goal is to have a commitment to move these two priorities forward and help us to make each day the best possible day for people living with and affected by ALS.

PILLAR SIX GOVERNANCE



Heather Haddow

Ensuring visionary direction and planning insightful decision-making, and effective operations of the Society.

The Board of Directors governs the affairs of the Society and sets the vision and mission to serve those living with ALS. The board is made up of 11 passionate volunteers who have all been affected by ALS in some way.

In 2013, the Board of Directors met to review and update our five year strategic plan, a culmination of twenty-five years of vision, compassion, leadership and dedication.

One of the many leaders on the Board of Directors is Heather Haddow. We had the pleasure of welcoming her to the ALS Society of Alberta Board of Directors in 2010.

Heather is married and has two children. She is active in the community and unselfishly gives of her spare time to causes that are close to her.

She is the Associate Vice President of Human Resources at Mount Royal University. In this significant leadership role, Heather guides, supports and leads the management of human resources for one of Alberta's newest universities.

Heather became passionate about the ALS cause after being touched personally by ALS. We often hear ALS is a rare disease but Heather experienced ALS three times. Unfortunately, she personally witnessed how cruel ALS is on the person and the family. Heather's experience drove her to get involved with the ALS Society. From our first meeting, we knew Heather would be a gift to the Society.

Heather has been on the ALS Society Board of Directors for four years. She has shared her knowledge, expertise and compassion to help us make each day the best possible day for people living with ALS.

She has given freely of her limited time to help expand the foundation of the Society and advised and guided our human resources strategic implementation. Heather plays an integral role on the Board of Directors and is a wonderful example of how our volunteers contribute greatly to the ALS Community.

PILLAR SEVEN

MANAGEMENT VOLUNTEERS & RESOURCES

Managing the organization's human, financial and physical resources in an effective and efficient manner primarily based on clients' needs and priorities.

Dina Bottrell (Coers)



The ALS Society has a dedicated group of over 100 volunteers for a variety of activities including support group facilitation, advocacy, resource development, computer programming and maintenance. Dina Bottrell, Vegreville WALK for ALS Volunteer Coordinator is a leader among our many volunteers.

In 2012, Dina Bottrell already had her plate full. Her fiancé Todd Bottrell was serving in the military in Afghanistan at the time, and she had to take on full responsibility for their young son. In addition, Dina worked full-time in Admissions/Records for Alberta Health Services. In her spare time, Dina was in the midst of planning her wedding, originally set for some time the same year.

Anyone can see that this would have been a full schedule, along with the added anxiety for the safety of her fiancé. Some people, however, can reach deep inside themselves for the energy to fuel their passion for something, or someone who is very important to them. This is how it was for Dina; her brother Colby had been diagnosed with ALS in June 2009 when he was just 18 years old.

Dina first attended the Edmonton and Grande Prairie WALKs for ALS in support of Colby, who enjoyed attending in the earlier days of this disease. It wasn't long before Dina could see that it would be much more beneficial to Colby if she were to bring the WALK to him, so that it would be easier for him to participate, and their family and Colby's friends could be there to support him.

On August 18, 2012, Dina, her sister Kayla, and their family hosted the first annual Vegreville WALK for ALS. The community rallied around the Coers family and the event raised over \$26,000 and saw over 100 people attend! Colby has the honour of cutting the ribbon each year at the Vegreville WALK for ALS and asks that others living with ALS join him in this honour.

Despite being diagnosed with this devastating disease, Colby still stays positive and keeps busy by helping coach the Vegreville Vortex Football team. Not surprisingly, the football team comes out to volunteer for Dina and participates annually. In 2013, the Lieutenant Governor, His Honour Donald S. Ethell and her Honour, Linda Ethell attended the Vegreville Walk. They were very impressed by the organization and the up-beat energy of the walk.

Dina is a wonderful illustration of the passion and dedication of our many volunteers that work tirelessly to help us reach our mission and vision.

AWARDS & VOLUNTEER RECOGNITION



Jan Desrosiers, Megan Blomfield, His Honour, Col. (Ret'd), The Honourable Donald S. Ethell Lieutenant Governor Of Alberta

Volunteers and long term employees were recognized at our annual appreciation event in November. We recognized the valuable contributions that our volunteers and employees have made to the Society throughout the years.

2013 Long Term Service Awards for Staff & Volunteers

- Jane Rivest, Client Services Coordinator – 15 years
- Cathy Martin, Past Chair of the ALS Board – 10 years
- Janice Zoeteman, Client Services Coordinator – 10 years
- Megan Blomfield, Client Services Coordinator – 5 years
- Dave Williams, Board Member – 5 years
- Norm Pollock, Past Board Member – 5 years
(Presented posthumously to Norm's family)

It Only Takes A Moment

*It only takes a moment to reach out to be a friend,
but to the ones who need you, the memory never ends.
A simple act of kindness for those people you don't know
may plant a seed of hope that for them will always grow.
We sometimes lose perspective of the difference we can make,
when we care more about our giving and care less of what we take.
So remember that your actions may help change lives someday.
Always think about the people that you meet along the way.
For it only takes a moment to reach out to be a friend,
but to the ones who need you, the memory never ends.*

~Anonymous

TREASURER'S REPORT

P.J. (PAT) MERZ

YEAR ENDED DECEMBER 31, 2013



I am pleased to report on the financial position of the ALS Society of Alberta. The Society had another very strong year in revenue generation, cost control and continues to maintain a strong balance sheet, which will allow the Society to meet its ongoing cash flow needs.

Revenue for the year is at \$2.67M which is 19.1% greater than planned revenues. The increase was mainly due to unexpected donation revenues and additional registrations, donations, and pledges from the WALKs for ALS and Betty's Run for ALS, along with revenues from third party fundraisers. Revenues continue to show strong growth considering the climate and grew 5.1% over 2012. Major events continue to generate approximately 49% of the total

revenues whereas third party events and donations both contribute 18% of the total revenue or 36% collectively. The other important main stream of revenue the Society continues to focus on is fundraising activities.

The total expenditures of \$2.1M were controlled to be slightly under budget for the year. The Society continues to allocate significant expenditures in equipment purchases, client services and research, which made up 57% or \$1.2M of the total expenditures in 2013. These vital supports and services truly make a difference every day to those living with ALS and their families. The Society's contribution in 2013 to the National research program was \$421k (\$88k higher than originally planned) which allows the researchers to continue to focus on their programs in finding the cause and cure for ALS. Ongoing efforts were made to control the operational costs and are within 1% of the budget and only account for 14% of the overall expenditures.

The Society continues to be in a very strong financial position with \$3M in current assets (mainly cash and short term investments) and another \$.7M in Net Capital Assets. At the end of 2013 the Society received a significant bequest from the Dutton estate. Approximately one half of the bequest was received at the end of 2013 and the balance is expected to be received in 2014. The bequest was designated to be used for the Society's equipment program.

These strong financial results are a reflection of the Society's strong, dedicated staff and group of hard working volunteers that truly make a difference every day in the lives of people living with ALS. I look forward to another successful year in 2014.

*P.J. (Pat) Merz, CGA
Treasurer, ALS Society of Alberta*

TRIBUTE TO THOSE WE'VE LOST

BEAUTIFUL FRIEND

Hello my beautiful friend
I've come to see you again
And as much as I try I can't say goodbye
When it's time to go I'll just say hello
Hello my beautiful friend
If you could be judged
By how much you're loved
And how much we've learned
From the love you've returned
You must be a friend
A friend among friends
And if your worth
while on this earth
can be measured in part
by the weight of my heart
You must be a friend
A friend among friends
Hello my beautiful friend
I've come to see you again
And as much as I try I can't say goodbye
When I leave to go I'll just say hello
Hello my beautiful friend
And for somewhere to cry
when things go awry
When it's all too much
I can feel your touch
and hear you say
go on lean my way
Hello my beautiful friend I've come to see
you again
And as much as I try I can't say goodbye
When you leave to go I'll just say hello
Hello my beautiful friend

This song was written by local Albertan and working musician, John Wort Hannam for his best friend Ken Rouleau (1968-2012) who passed away from ALS. You can hear the song on his website at johnworthannam.com



~JOHN WORT HANNAM



The ALS Society of Alberta

Provincial Office
Suite 250, 4723 1 Street SW
Calgary, Alberta T2G 4Y8
403-228-3857
1-888-309-1111

Edmonton Office
5418 97 Street NW
Edmonton, AB T6E 5C1
780-487-0754
1-866-447-0754

Charitable No. 12063 0827 RR0001

Audited Financial Statements are available upon request