



ALS SLA

ALS SOCIETY OF MANITOBA
LA SOCIÉTÉ MANITOBAINE DE LA SLA

2014-2015 Annual Report

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WINNIPEG, MB R3H 0H2
PHONE: 204.831.1510
www.ALSMB.ca

ALS Society of Manitoba was founded in 1980 for persons with ALS/MND, their families, friends and other interested parties. During the past 35 years, the Society has helped clients and their families, by providing information and support. As our organization continues to grow, we are able to offer a more client-service based program which helps those living with ALS/MND maintain independence and make informed decisions about their care. Our mandate is to make a difference in the lives of those living with ALS/MND every day.

VISION Improved Quality of Life for all people affected by ALS/MND.

MISSION Helping Our People Everyway we can by:
Investing in Research
Providing Client Services

CORE VALUES **Respectful** ---- We respect the rights of people impacted by ALS to live with dignity and make their own decisions;
Responsible & Ethical ---- We commit to continuous improvement, accountability, and sharing of knowledge.

THREE YEAR PRIORITIES AND GOALS (2013-2015)

- 1. Ensure long-term financial stability of the Society**
Annually balance the Society's consolidated budget.
Secure consistent and reliable funding.
Increase our fundraising capacity.
- 2. Maintain leadership in provision of client services**
Ensure programs are relevant to client's needs.
Maintain a sustainable quality of care.
Improve access to the Society's services throughout Manitoba.
- 3. Strive for Organizational Efficiency and Excellence**
Have a diverse, skilled, knowledgeable, and engaged Board of Directors.
Have the correct complement of staff.
Continuously improve the Society's physical work environment.
Attract, recruit and retain volunteers.
Develop a plan to codify and transfer staff knowledge.
Develop a plan to codify and transfer volunteer knowledge regarding events.
- 4. Increase awareness and profile of ALS & the ALS Society throughout Manitoba**
Increase profile with the general public to increase our volunteer and donor base.
Increase profile with clients & caregivers to increase awareness of services.
Increase profile with health care professionals to enhance recognition of ALS and provide the best possible care.
Increase profile within Government to ensure long term support and funding.
Increase profile with funding agencies, service organizations and the business community to secure sustainable funding.



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2013-2014 BOARD OF DIRECTORS

President: Janelle Batters
Past President: Lorna McLeod
Treasurer: Mike Ehinger

Directors: Ruth Boyd
Kevin Branch
Micheline Chaput
Dawn Harrison
Kelsey Jackson
Sara Koroscil

Alison Logan
Jessica Lorusso
Ernst Schell
Victor Perrin
Grant Zipursky



STAFF

Executive Director & Client Services Coordinator: Diana Rasmussen
Client Services Coordinator: Angela Hallam
Office Manager: Sharon Carter
Events and Fundraising Coordinator: Leila Dance

REPORT FROM BOARD PRESIDENT

2014-2015 was a dynamite year for ALS/MND awareness. The ALS Ice Bucket Challenge was unprecedented in its ability to create international awareness about the effects of ALS. Thank you to everyone who participated in the challenge itself and in the social media campaign. We thank you for your continued support.



Our board and the staff at the ALS Society of Manitoba are committed to working hard to help our clients, families, and the entire ALS/MND community. Some local highlights of the past year include:

- Relocating our office to a facility that is better equipped to enable us to serve our clients. There is ample space to store all the 2400 plus pieces of equipment we loan to our clients, it is also a more welcoming and functional environment to serve our clients, volunteers and the ALS community.
- Our walks continued to be a great success enabling us to continue to provide funds to ALS Canada to invest in research through the Scientific Medical Advisory Council, and provide Client services to those affected with ALS and those caring for someone with ALS, their families and friends.
- Our Cornflower Gala and our Drive for Life Golf Tournament continued their tradition of success. We are so grateful to have fabulous volunteers who continue to give of their time.
- The Evening with Goldeyes continued to be beneficial for raising awareness of ALS within our communities, helping us further our abilities to secure support for addressing the challenges and hopefully making ALS a treatable disease, while we work towards a cure.

Incidences of ALS/MND continue to rise in Manitoba and across Canada. Today, there are approximately 289 individuals living with ALS/MND across Manitoba. Our client base continues to become more diverse in age and geography adding unique challenges to client service delivery. Continuous fundraising is required in order to ensure we have the funds and staff available to provide equipment and services to all clients no matter where they live.

I would like to thank the Board of Directors, our donors, corporate partners, the Winnipeg Regional Health Authority, our volunteers, and our hardworking staff for their continued dedication and commitment to serving the ALS/MND community.

With the continued support from the Manitoba community, the ALS Society of Manitoba will continue to grow and provide services to individuals living with ALS/MND, their families, and work towards finding a cure.

Janelle Batters
President



REPORT FROM EXECUTIVE DIRECTOR

A year that came and went with so much activity. We are so fortunate in Manitoba to have so many people that are committed to the programs and services that the ALS Society of Manitoba offers. Thank you Volunteers!!!

Our Mission is one of HOPE – Helping Our People Everyway we can!

Every person diagnosed with ALS/MND is one too many -- that is what a client and family told me recently and of course we totally agree.



The ALS Society of Manitoba is here for the whole journey, from diagnosis to support services including our Equipment Lending Program, Transportation, Counselling, accommodation at the Brummitt Feasby ALS House, Respite to Grief Counselling. We are Helping Our People Everyway we can.

How families handle a diagnosis of ALS/MND and the challenges it can bring differs from one person to another. What we do know is that with good communication about the needs, wants and quality of life for each person is really important. The impact of the diagnosis and how that is relayed to clients and families is also important. Some people will want to know more than others, some will want to know very little, and some will need time to digest and explore options. Some don't want to know anything at least for now.

The ALS Society of Manitoba also provides educational programming for professionals, non-professionals, clients, families, friends and rural communities of this great province through our Client Services Coordinators. We support those living with ALS/MND in order to help them maintain their quality of life while managing day to day and troubleshooting the issues of daily living - that is what the ALS Society of Manitoba does.

This past year, our fundraising and awareness of the ALS/MND has surpassed prior years. With the ALS Ice Bucket Challenge came a gift of HOPE and we thank each and every one who participated, as we do for all of our fundraisers that help us help those living with ALS/MND. Whether it be a Lemonade Stand or Third Party Golf Tournament, the WALKS for ALS, the Cornflower Gala, the Lite Up a Life Campaign at the ALS House, a raffle or dance and many other events, you are the people that make a difference so we can, as a small not for profit, continue our Mission of HOPE – Helping Our People Everyway we can.

Thank you for a great 2014/15!

Diana Rasmussen
 Executive Director

BRUMMITT-FEASBY ALS HOUSE

A home for persons living with ALS/MND, this house is the first and only one of its kind in North America.

The Brummitt Feasby ALS house is a home where persons living with ALS/MND realize their full potential in an environment that respects their rights and dignity. There is twenty-four hour care, specialized treatment, administration of medications, meal preparation, housekeeping and laundry, recreation activities, arrangements for appointments and specialist services, ongoing assessment and intervention and a Care plan designed to meet each individual.



CLIENT SERVICES

Children, Youth and Young Adult's Program

Part of the ALS Society of Manitoba's mission is to support the whole family, including children. It is important that supports are given to all age groups of families and therefore the Children's Program is an integral part of our services.

In 2014, the ALS Society of Manitoba sent one young adult to attend the Annual ALS Youth Retreat at beautiful Dallas Valley Ranch Camp in Regina, Saskatchewan.

Client Services Coordinators

The Client Services Coordinators provides information and education about the nature and management of ALS/MND, as well as information regarding local and provincial health care services and social and community resources. The Client Services Coordinators may also provide an assessment of a client's ongoing needs and advocate with appropriate services as required such as home care, physicians, the ALS/MND Clinic Team and other services.

Emergency Response Information Kit (ERIK)

ALS Society of Manitoba has emergency response information kits available for all persons living with ALS/MND. The kit includes a health information form, and a health care directive form.

Equipment Lending Program

Our Equipment Lending Program is designed to help people cope with the daily challenges of decreased mobility and independence, by providing basic and essential assistive equipment, which includes mobility equipment, lift equipment, bathroom aids, etc. All equipment loaned is available at no charge to the families. Currently, the ALS Society of Manitoba has over 2400 pieces of equipment.

LVR (Breathing Bag) Program

The LVR Bags are provided by the ALS Society of Manitoba at no cost to clients and will be given out by the Respiratory Therapist at the ALS/MND Clinic.

Research

The ALS Society of Manitoba supports the ALS Canada National Research Program. Last year, \$411,000.00 was sent to help fund research by the ALS Society of Manitoba.

Resource Library

The Society's library consists of books, videos and brochures about ALS/MND, individual experiences with the disease, coping with disabilities and grief. There are also a number of booklets on strategies for breathing, eating, drinking and swallowing as well as information on communication and mobility.

Support Groups

Support groups provide an open, friendly environment for clients, families and friends to learn more about living with ALS/MND. The group meets once a month throughout the year (except December). Meetings may include a guest speaker or focus on specific topics, as well as informal discussion and refreshments.

Tube Feeding Bag Program

The ALS Society of Manitoba provides tube feeding bags, different size syringes and any connectors if needed, plus other supplies at no charge to clients.

Volunteer Family Advocate Friend (VFAF) Program

The VFAF program is a program designed to match trained caregiver support volunteers to a person living with ALS/MND and their family members. These volunteers would provide practical assistance and advocate for the care giving family, saving them time, energy and allowing them to focus on their relationships and major issues of care.

ALS ICE BUCKET CHALLENGE

The ALS Societies around the world were the generous recipients of a viral social media phenomena this past summer known as the ALS Ice Bucket Challenge. This challenge involved dumping a bucket of ice water on your head to promote awareness of ALS and encourage donations to local ALS Societies. The challenge also encourages nominated participants to be filmed having a bucket of ice water poured on their heads, uploading it to social media pages and then nominating others to do the same.

The origins of the idea of dumping cold water on one's head to raise money for charity started with a young baseball player, Pete Frates. Pete is a Bostonian who was diagnosed with ALS in March 2012.



The ALS Society of Canada was pleased to announce in November a total of 16.2 million dollars raised through the ALS Ice Bucket Challenge in Canada. Based on a partnership with Brain Canada, the ALS Canada earmarked \$10 million to research, which was matched by Brain Canada to bring the total to \$20 million to ALS Research in Canada.

At the ALS Society of Manitoba, we are pleased to announce that over \$350,000 was raised in Manitoba by over 6,000 donors from the ALS Ice Bucket Challenge. The Society is putting those donations to work by supporting research and families on their journey with ALS.

“The ALS Ice Bucket Challenge was a supreme gift and gives hope to those who battle this fatal disease,” says Diana Rasmussen, executive director for the ALS Society of Manitoba. “We are extremely grateful for the amazing support given throughout the province. Thank you Manitoba!”



EVENTS



Cornflower Gala Dinner Saturday, April 12, 2014 St. Charles Country Club

This event was a huge success, and helped raised much needed funds for ALS support and client services here in Manitoba. The night's success can be attributed to the almost 200 guests that ate a delicious meal prepared by St. Charles Country Club, bid on top prizes including two tickets anywhere WestJet flies or a trip for two to Churchill, and danced the night away to the live music by the Luke and Murray Two Man Band.

Walk for ALS - Winnipeg Saturday, May 31, 2014 Assiniboine Park

More than 1600 people that came out to support the ALS Society of Manitoba for its annual Walk for ALS. This year's the Walk received support from The Real Canadian Superstore and Extra Foods in the amount of \$32,000! Thank you to the generous Walkers, supports, sponsors for helping us raise over \$200,000 for client services and research.



An Evening with the Goldeye's ALS/Lou Gehrig Night Friday, June 14, 2014

Seventy-five years ago, on July 4, 1939, Lou Gehrig delivered what is now known as sports' most famous speech. Each year the ALS Society of Manitoba partners with the Winnipeg Goldeyes to recreate that memory. Local actor, Justin Otto re-enacted the famous farewell speech of the "Iron Horse", followed by the ALS Society of Manitoba's volunteers passing the helmet to raise funds for support services offered here in Manitoba to those living with ALS. This year's event raised over \$3,000.00 and even with the rain many showed their ongoing support to this life changing disease.

Flag Raising Ceremony June 19, 2014 Winnipeg City Hall

In honour of June being ALS Awareness Month



Walk for ALS - Belmont Saturday, June 28, 2014 Strathcona Drop In Centre

The Centre was full of excitement as families, friends, walkers, volunteers and Bertha Buote, Walk Coordinator raise well over \$5,000 to support client services and research. Each year, Belmont takes a moment to remember those who have lost the battle with ALS/MND.





**AGM/Volunteer Appreciation Evening
Wednesday, June 25, 2014
Victoria Inn Hotel & Convention Centre**

We would like to take this opportunity to thank all our volunteers, those on our board of directors, those that volunteer on committees and those that dedicate countless hours to making sure all our events are successful. The Volunteer Appreciation Evening included tasty fruit and cheese platters, hot and cold beverages and wine which were enjoyed by staff, board and volunteers alike. It was a wonderful evening with the chance to see old friends and meet new ones.



**10th Annual Drive for Life Golf Classic
In memory of Marcel Bertrand
Thursday, September 4, 2014
Bel Acres Golf and Country Club**

The rain might have delayed the start of our tournament but it certainly didn't stop the golfers, sponsors and volunteers from having a great time during the day. With the 11th Annual Drive for Life Golf Classic completed, we are please to announce that we raised over \$66,000.00 for people living with ALS in Manitoba.



**ALS Giant Yard Sale
Saturday, August 23, 2014
Gloria Dei Lutheran Church**

This years event was a huge success and raised over \$3,000.00! The inside of Gloria Dei Lutheran Church was filled with thousands of lost treasures waiting for a new home and the people lining up before the doors opened were ready to find that special something.



**Lite Up a Life
Lighting Ceremony - Wednesday, December 10, 2014
Brummitt-Feasby ALS House**

During this time of year, the opportunity to make a donation in memory of those that have passed, those living with, and those who are being diagnosed with ALS is so important. Your support will continue to have a huge impact on the ALS community for the years to come.



**We Moved!
March 24, 2015**

This new space is located at 2A – 1717 Dublin Avenue. This new space offers us a formal boardroom, a family resource room, complete with a library filled with ALS resources and plenty of warehouse space for our over 2400 pieces of equipment!

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THIRD PARTY EVENTS

A unique and wonderful way to give to the ALS Society of Manitoba is through holding a Third Party Event. These fundraising events are planned from outside parties who give the proceeds to The ALS Society of Manitoba.

There are so many creative ideas such as walk-a-thons, head shaving, bowling parties, garage sales, bake sales, fashion shows, concerts, comedy nights, car washes, BBQ, “wear jeans to work day”, or a “dress up day at work” or simply hosting a dinner where instead of gifts, guests make a donation to the ALS Society of Manitoba.

Altec Christmas Party
 BDO Dunwoody's Jeans Day
 Gardiner Open
 Henry Derksen Memorial Fishing Derby
 Henry Derksen Memorial Golf Tournament
 International Facility Management Association Golf Tournament
 Kiazyk Horseshoe Tournament
 Pumpkin Ceilidh
 Robert and Doreen Dick Memorial Ski-a-thon
 Special Love Party by an ALS Family
 Transcona Collegiate Late to Class Fee
 Vipond Golf Tournament

GRANTS

Rotary Club of Winnipeg Assiniboine The ALS Society of Manitoba was awarded funds to support the Brummitt-Feasby ALS House.

Investors Group - Murial Joyce Sinclair Foundation The ALS Society of Manitoba is awarded funds to support general costs.

Winnipeg Foundation The ALS Society of Manitoba received funding to support equipment and medical supplies purchased to support those living with ALS.

The ALS Society of Manitoba also received numerous endowment funds through the Winnipeg Foundation, including the Dr. J.E. Morris Manitoba ALS Society Fund, the Edward Bell Fund, the Benjamin Doupe Fund and the George Waters Fund.

VOLUNTEER SPONSORED GRANTS

These funds are received based on the number of hours volunteers give to the ALS Society of Manitoba through their employer.

CN Corporate Services The ALS Society of Manitoba was awarded funds to support general costs for Client Services.

RBC Royal Bank The ALS Society of Manitoba was awarded funds to support general costs for Client Services.

FRANK EDMONDS VOLUNTEER AWARD

The Frank Edmonds Volunteer Award is given annually to a volunteer with the ALS Society of Manitoba whose commitment and dedication to the cause of ALS has been noted by their peers. The award is in remembrance of Frank Edmonds who died of ALS in 2001 and was given in his name by his daughter Tracy Edmonds-Leckie.

This year's presentation of the Frank Edmonds Volunteer Award was divided into two categories:



The Winnipeg Award went to:

Murray Jordan (Left)

The Rural Award went to:

Bertha Buote

MARCEL BERTRAND MEMORIAL BUSINESS AWARD

After being diagnosed with ALS in February of 2000, Marcel Bertrand worked tirelessly on behalf of the ALS Society of Manitoba, taking on such roles as board member, educator, advocate and major fundraiser. Marcel served two terms as president of the ALS Society of Manitoba and was instrumental in the planning and reconstruction of Brummitt-Feasby ALS House. Marcel received numerous local and national commendations for his work with the Society before his death in July 2007.

In recognition of Marcel's exceptional ability to garner support from the business community for his work, this award is presented annually to honour a business which has made a significant contribution both in volunteerism and financial support to the ALS Society of Manitoba and people living with ALS.



The 2014 recipient was:

Real Canadian Superstore and Extra Foods

Erwin Bagos, Ryan Marian, Al Jasper, Laura Lee Crofton, Casey Hellard, and Rob Almeida (L-R)

REPORT FROM TREASURER

Financial Summary

In the fiscal year ending March 31, 2015 (F2015), the ALS Society of Manitoba recorded revenues of \$1.202 million, which was approximately an 11% increase. Contributing to this increase was the timing of the Cornflower Gala (was moved from March to April, thus not being in F2014), and the success of the ALS Ice Bucket Challenge. After adjusting for these two items, revenue was relatively consistent with the prior year.

Expenses were \$1.211 million, which was an increase as well due to the items mentioned above (timing of the Cornflower Gala, ALS Ice Bucket Challenge), and various operational changes.

Overall this resulted in a net loss consistent with the prior year.

Fundraising Events

After multiple years of consistent growth, in F2015 we tracked short of our budgeted increase on some of our major fundraising events such as the Walk and Golf Tournament. However, it is important to recognize that the events still performed well overall and we are extremely grateful for all the support from volunteers and staff that help make the fundraising events such a success year after year.

Additionally, these results were offset with unexpected revenue from the ALS Ice Bucket Challenge. The end result was that our overall fundraising revenues were higher than F2014 (even after adjusting for no Cornflower Gala in F2014) and on track with our overall budgeted revenue goals for the year. However, certain ALS Ice Bucket Challenge funds were also recorded on a net-of-expenses basis for accounting purposes, so the actual cash received was higher than revenue recorded for accounting (see below).

Client Services and Research

From the ALS Ice Bucket Challenge donations (\$423,000), we were able to commit \$338,000 to research and \$85,000 for client services. Combining this with our \$73,000 commitment to research from our Walk donations, resulted in a commitment of \$411,000 to funding research expenses overall.

The demands for equipment and support continue to increase as they number of people living with ALS in Manitoba increases. In F2015 we were able to fund over \$78,000 of purchases of new equipment, in addition to other various client services.

Designated Revenues

Approximately \$130,000 of designated revenue was recorded on the income statement in F2015. This was mostly due to recognizing designated revenue for client services to the maximum extent possible, being the amount of client service expenses in the year. This leaves roughly \$348,000 of designated revenue still remaining on the balance sheet.

I would like to thank our staff as well as the numerous volunteers that made our year such a success. I would especially like to thank our donors for their contributions and continued support of the Society, as without them we would not be able to provide the valued programs and services to our clients.

Mike Ehinger
Treasurer



NOTES

PROUD SPONSORS OF THE ALS SOCIETY OF MANITOBA

B & L Resources for Children, Youth & Families

Boston Pizza
BSD Solutions
Canexus Corporation
CJOB
Construction Labour Relations Association of Manitoba
CTV
Derksen Plumbing & Heating
DMS Industrial Constructors Inc.
Domino's Pizza
E.H. Price
East Side Ventilation
Emco Corporation
Ernst & Norma Schell and Family

FWS Group of Companies

Golf Dome
Johnston Group Inc.
King's Transfer
MacDon Industries
Manitoba Blue Cross
Manitoba Liquor and Lotteries
McDonald's Restaurants of Canada Ltd.
Metro News Winnipeg
Price Industries Limited
Real Canadian Superstore and Extra Foods
Red River Co-Op
Water Mart
Wolseley Canada *Mechanical Business Group
WOW! Hospitality Concepts

Apex Distribution
 BDO Canada
 Biff's Septic & Portable Toilets
 Cambrian Credit Union
 Canadian Beverage Container Recycling Association
 Charleswood Roofing
 City of Winnipeg
 Cottage Bakery
 Credit Union Central of Manitoba
 Current Restaurant
 D & S Industrial Inc
 Dan The Magic Man
 Diamond Athletic Medical Supplies Inc
 Grey Wall Photography
 Gunn's Bakery
 Home Run Sports
 Investors Group

Joe Black Coffee Bar
 KB FuJuMelody - K.O.T Productions
 Keg Steakhouse & Bar
 Lawson Sales Ltd.
 Light Visions
 Lobby on York
 Long and McQuade
 Manitoba Nurses Union
 Midwest Engineering
 Moxies
 Moxie's Classic Grill
 Mr. Lube
 MTS Clowns
 Oma's Bake Shop
 Onyx Financial Group
 Parkside Ford
 Party Stuff

Pembina Insurance
 Pet Value
 Plumbers and Pipefitters Union -
 United Association Local Union 254
 PMA Canada Ltd.
 Prairie 360 Skyline Restaurant and
 Lounge
 Princess Auto Ltd
 Rae & Jerry's Steakhouse
 Red River College
 Round Table Steakhouse
 Stephen N Rosenfield, CGA
 Stride Ahead Sports
 The Elektrik Chair
 United Rental
 Victaulic Company of Canada Ltd.
 WPS - Community Relations

Without the generous support of those listed above, our annual events would not be possible. Please take the time to support those that support us and let them know that because of their dedication to the ALS Society of Manitoba you are supporting them by using their services!