



ALS SLA

ALS SOCIETY OF MANITOBA
LA SOCIÉTÉ MANITOBAINE DE LA SLA

2013-2014 Annual Report

ALS Society of Manitoba was founded in 1980 for persons with ALS, their families, friends and other interested parties. ALS (Amyotrophic Lateral Sclerosis), also known as Lou Gehrig's Disease is a life limiting disease where 90% of people diagnosed will die within three to five years, some within a few short months. During the past 33 years, the Society has helped clients and their families, by providing information, education, equipment, 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 maintain independence and make informed decisions about their care.

VISION

A cure will be found and persons living with ALS will realize their full potential in a society that respects their rights and dignity.

MISSION

HOPE is important in the lives of those impacted by ALS, so we Help Our People Every way we can.

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, confidentiality, accountability and transparency in all we do.
Responsive & Supportive - We provide people impacted by ALS excellence in support, services and up-to-date accurate information.

THREE YEAR PRIORITIES AND GOALS

- 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: Sara Koroscil

| | | |
|-------------------|------------------|-----------------|
| Directors: | Chris Albi | Alison Logan |
| | Ruth Boyd | Jessica Lorusso |
| | Kevin Branch | Victor Perrin |
| | Micheline Chaput | Paul Simms |
| | Dawn Harrison | Grant Zipursky |
| | Kelsey Jackson | |

STAFF

| | |
|--|------------------|
| Executive Director & Client Services Coordinator: | Diana Rasmussen |
| Client Services Coordinator: | Angela Hallam |
| Office Manager: | Sharon Carter |
| Events and Fundraising Coordinator: | Leila Dance |
| Volunteer Coordinator: | Deloree McCallum |
| Digital Marketing Coordinator: | Paul Duque |
| Brummitt-Feasby ALS House Manager: | Amy Rodgers |
| Bookkeeper: | Mandy Kashton |



2013-2014 continued to be a success for the ALS Society of Manitoba. The hard work and dedication of our staff, volunteers, sponsors, and donors is paramount in this success. Thank you all!

Some highlights of the past year include:

- University of Manitoba researchers Dr. Geoff Hicks, Dr. Songyan Liu, and Ph.D. student Yueqin Zhou made a discovery as to how and why a mutated gene causes ALS; their research was published in the journal of PLOS Genetics. This discovery will in part help overall research into the cause of ALS.
- \$219,647 was raised from the Winnipeg and Belmont Walks. ALS Manitoba contributed \$76,351 of Walk proceeds to ALS Canada to fund research.
- Drive for Life Golf Tournament was another fundraising success. This was further enhanced by numerous third party events held throughout the year.
- The ALS Conference and the Evening with Goldeyes continue to be beneficial for raising awareness of ALS within our community, helping us further our abilities to secure support for addressing the challenges and finding a cure and treatment for this disease.
- Services to the ALS Community at large increased dramatically in the area of equipment and counselling.

The incidence of ALS continues to rise in Manitoba and across Canada. Today, there are approximately 276 individuals living with ALS 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 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, their families, and work towards finding a cure.

Janelle Batters
President



An integral part of any year is meeting clients, families and their friends as well as sponsors, donors, volunteers, the public and the many people who come into our lives because they have been touched by ALS.

We said goodbyes to those who fought a hard battle with ALS and embraced those who lived on and were coping with loss.

In striving to meet our Mission we continue our commitment of HOPE – Helping Our People Every way we can.

The Board of Directors, Executive and Committees continued to meet regularly and do their due diligence to give guidance and assistance to meet our Goals and Objectives.

Programs for Clients and Families have been maintained, with Client Services, Counseling, Education, Children's Programming, Support Groups, Library, Tube feeding and Breathing bag program, and Equipment program which saw a massive increase in the amount of equipment going out to clients all over the province.

Brummitt-Feasby ALS House continues to be a viable option for a Home like Setting with Care and Support for those whose needs cannot be met at home.

In 2013, we said goodbye to Anrea Zaslov, Events and Volunteer Coordinator and made some significant changes to our Human Resources, by splitting positions and consequently welcoming Leila Dance as our Event and Fundraising Coordinator full time and also a little later Deloree McCallum as our part time Volunteer Coordinator.

Amy Rodgers continues as our Brummitt-Feasby ALS House Coordinator, Angela Hallam our Client Services Coordinator, Sharon Carter as Office Manager and Paul Duque as Digital Marketing Coordinator.

Programs and Human Resources cost money and with ever increasing numbers of clients to be supported we need to make sure that we have a cohesive team of Staff. Fund Raising, Best Practices, Continuing Education, Communication are all inherent in the jobs we do and I can not thank my staff enough for the time and effort that all of them give over and above the hours they normally work.

We thank all our donors, sponsors, corporate partners, our health related partners, WRHA and all the organizations with whom we work. Without these relationships we would not be able to help those living with ALS. We look forward to working with all of you in 2014-15.

Diana Rasmussen
Executive Director

Brummitt-Feasby ALS House, a home for people living with ALS, officially opened on January 14, 2005. This house was and still is the first of its kind in North America for persons living with ALS.

This home is where persons living with ALS realize their full potential in an environment that respects their rights and dignity. It provides quality care for residents and respite for ALS patients and their families.

Twenty-four hour care is provided including, specialized treatment, administration of medications and meal preparation, housekeeping and laundry, recreation activities, arrangements for appointments and specialist services, ongoing assessment and intervention and a Care Plan designed to meet the needs of our residents.

2013-14 was a busy year with new long term and respite clients. Increasing the efficiency and effectiveness of Brummitt-Feasby ALS House is first and foremost in terms of operation of the ALS House. This in turn has assisted us as we try to make each person's stay at this wonderful home, the best that it can be.

Through hard work, determination and strengthened relationships with the WRHA, Palliative Care, Home Care, Community Therapy Services and the ALS/MND Clinic we have seen strong collaboration and commitment.

The staff at the ALS House mourned the loss of a number of clients during 2013-14. At the same time, we met and cared for new clients over the year. These changes and challenges allowed us to improve in providing quality service to our clients. We fondly remember those who have passed and their families and hope that families will stay in touch and support this one of a kind house.

We continue to strive in the provision of excellence of care for those living with ALS/MND.

Diana Rasmussen
Executive Director/Client Services Coordinator



As in the previous year, the number of clients diagnosed with ALS continues to increase. Our services try to meet the unique needs of clients, however clinical services, equipment, support services and education requirements also have increased.

In addition to overseeing the general operations, administration, human resource, fundraising, and volunteer activities of the ALS Society of Manitoba, the Executive Director is also charged with providing client services throughout the province. The ALS Society of Manitoba offers the following programs to people living with ALS and their families' across the entire province:

- Equipment Lending Program continues to have substantial increases. Request and needs of clients are ongoing;
- LVR (Breathing Bag) Program: ALS Manitoba purchases bags and educates clients and caregivers to use them;
- Tube Feeding Bag Program: ALS Manitoba purchases tube feeding bags for clients;
- Education & Counseling Program: ALS Manitoba provides education and counseling for clients and families, including manuals, brochures, books, and other resources;
- Children's Program: ALS Manitoba provides education and opportunities for discussion for children of ALS clients. Referrals to outside sources for assistance are also provided as well as a Bursary Program for children/youth;
- Support Group Program: ALS Manitoba hosts a monthly support group for clients and their families in Winnipeg, for those living with ALS and those who have lost a loved one. An expansion to other areas of the province is currently underway for these support groups;
- Library: The library is a resource for families, clients, students, and the general public;
- Client Services Visiting Program: Assists clients with their diagnosis and quality of life issues;
- Volunteer Family Advocate Friend (VFAF) Program: Links volunteers with specific clients to provide assistance for the client and their family and improve their collective quality of life.

With the assistance of Angela Hallam, Client Services Coordinator, programs are developed based on need. We thank all our sponsors, donors, clients and families, vendors and the community at large, who help us in this regard. New programs are also in the works for caregivers.

Diana Rasmussen and Angela Hallam
Client Services Coordinators

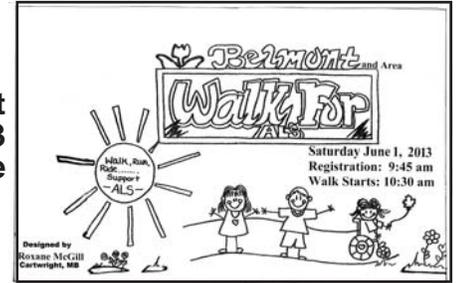


**Walk for ALS - Winnipeg
Saturday, June 1, 2013
Assiniboine Park**

The 2013 Walk for ALS was a huge success despite the moody weather. The energy in the South East Parking Lot at Assiniboine Park on June 1, 2013 was phenomenal. The demonstrated enthusiasm by walkers, volunteers, vendors and all those who contributed was inspiring. This year the Walk for ALS raised close to \$200,000 with the largest number of walk participants ever tallying up to 1500 walkers!



**Walk for ALS - Belmont
Saturday, June 1, 2013
The Clubhouse**



**Advocacy Day
June 2013
Manitoba Legislative Building**



**Flag Raising Ceremony
June 20, 2013
Winnipeg City Hall**

In honour of June being ALS Awareness Month

**AGM/Volunteer Appreciation Evening
Wednesday, June 26, 2013
Ramada Viscount Gort Hotel**

The Volunteer Appreciation Evening was a wonderful evening enjoyed by all and included tasty snack platters, hot and cold beverages and wine. The Society provided a very special thank you at all the volunteers that help in the last year with a certificate of appreciation and a plant for their garden.



**An Evening with the Goldeye's
ALS/Lou Gehrig Night
Friday, June 22, 2013**



Our very own Diana Rasmussen walked on the infield at the beginning of the game and didn't let a large crowd of eager baseball fans deter her from delivering a compelling rendition of the famous Lou Gehrig's Farewell Speech. The ball park was silent and Diana commanded a captured audience. Our Volunteers once again stood up to the plate, a perfect play on words here, and really gave it their all while passing the helmets at different sections at the ballpark.

An Evening with the Goldeyes is such a fun event, volunteers all have smiles on their faces and fans learn something about ALS - it is really a win-win!

ALS Giant Yard Sale
Saturday, August 24, 2013
Gloria Dei Lutheran Church

10th Annual Drive for Life Golf Classic
In memory of Marcel Bertrand
Thursday, September 5, 2013
Bel Acres Golf and Country Club



8th Annual Conference on ALS
“Lessons Learned - Living with ALS!”
Friday, November 8, 2013
Victoria Inn Hotel and Conference Centre

Guest Speakers include:

Nadir Kharma, MD, FRCPC
David Taylor, Ph.D.
Kerri Schellenberg, MD, FRCP(C)
Carol Scott, OT
Diane Rawluk, OT

Ali Logan
Mike Harlos, MD, CCFP, FCFP
Lori Embleton
Christine Newell



Lite Up a Life
Lighting Ceremony - Wednesday, December 11, 2013
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.

Great Dining Experience
Bud, Spud and Steak Fundraiser
Friday, February 7, 2014
Cowboy's, Canad Inn Windsor Park

Thank you so much to all those that came out and joined us at our Bud, Spud and Steak Fundraiser. This event, in conjunction with the Great Dining Experience Raffle, helped raise over \$7,000.00 for the ALS Society of Manitoba. All proceeds from this raffle went to the ALS Society of Manitoba's Equipment Lending Program – providing medical equipment to those living with ALS.



There was no Cornflower Gala Dinner during the 2013-14 fiscal year, the Board of Directors made the decision to move the event from March until April to accommodate dinner guests returning from winter holidays. The 2014 Cornflower Gala was held on April 12, 2014 and will be included in the 2014-15 Annual Report.

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.

Chapel Children’s Lemonade Stand
Henry Derksen Memorial Fishing Derby
Henry Derksen Memorial Golf Tournament
Home Care Centralized – Casual Friday
International Facility Management Association Golf
Gardiner Open
Investor’s Jeans Day
Larson Anniversary
Manitoba Marathon

Old Time Dance
Otis Canada Employee Jets Ticket Draw
Pumpkin Ceilidh
Robert and Doreen Dick Memorial Ski-a-Thon
Rotary Golf Tournament
Special Love Party by an ALS Family
Swingnons
Vipond Golf Tournament
Zumba for ALS

GRANTS

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

Manitoba Community Service Council The ALS Society of Manitoba was awarded funds to support operating costs associated with the Brummitt-Feasby ALS House. This grant included working four bingos at McPhillips Station and Club Regent Casino.

Mac’s Coin Box Program ALS Society of Manitoba was chosen for the Coin Box Program during the months of February and March 2014 at all Mac’s Stores in Winnipeg.

Manitoba Government Housing and Community Development The ALS Society of Manitoba was awarded funds towards the purchase of a generator for the Brummitt-Feasby ALS House.

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

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

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

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:

Greg Fritz

The Youth Award went to:

Madison, Aidan and Riley Chapel

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 2013 recipient was:

Tripwire Media Group

For the fiscal year ended March 31, 2014 we recorded revenues of \$1.082 million which was approximately 2% lower than the prior year. The Cornflower Gala which was moved from March to April in 2014 resulted in a decrease in revenue of approximately \$57,000 compared to last year.

Adjusting for the fact we did not hold a Gala in F2014, revenue increased \$35,000 or 3%. Fundraising and other donations (adjusted for the Gala) increased \$29,000 or 5%. We are extremely pleased that we generated increased revenue in our signature events - Walk for ALS and the Drive for Life Golf tournament.

We also generated increased revenue in third party events, In Memoriam and general donations. We are very thankful to all the groups and individuals who support us through third party events, many of them returning year after year.

Expenses of \$1.1M were basically flat to the prior year, once adjusted for the Gala expenses in F2013. The demands for equipment and support continue to increase as the number of individuals living with ALS increases. For the third consecutive year, we were able fund over \$60,000 of new equipment. In the last three years we have funded equipment purchases of \$188,000. We also sent over \$76,000 to ALS Canada to fund research from our Walk revenue.

Brummitt-Feasby ALS House operated at a small loss for the year, similar to the prior year.

From a Balance Sheet perspective, the Society is in a healthy financial position with \$422,000 in unrestricted net assets.

I would like to thank our staff at the Office and Brummitt-Feasby ALS House 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.

Sara Koroscil
Treasurer



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