



ALS SLA

ALS SOCIETY OF MANITOBA
LA SOCIÉTÉ MANITOBAINE DE LA SLA

Newsletter

Summer 2010

Our New Home



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EXECUTIVE DIRECTOR'S DIARY

Summer is here – yay!!!!!!!

The winter seemed to linger, however the ALS Society of Manitoba had a busy time as well as an eventful time over those cooler darker months.

Our client numbers continued to increase and that in itself meant that we needed to assist people with ALS with equipment, support and education as well as other services.

The Society was successful in securing a grant to make four videos and upgrade our website with the assistance of Tripwire Media, clients, families and of course our own Brian Campbell – Events and Volunteer Coordinator. These videos have been a tremendous help to families and we have been contacted by many people across the country thanking us for this help. For viewing go to our website at www.alsmb.ca.

We also moved our offices in March which has resulted in even greater liaisons with clients and families. Needless to say we are enjoying having a little more space to work and breathe as well as some privacy for clients and families.

We also received a major donation from a donor for Research and Client Services and this donation will make a huge difference for the Society in operating client services. We thank each and every donor who contributes to the organization so that the quality of life of people living with ALS can be made better.

Brummitt-Feasby ALS House has been full. Many people have waited patiently for a bed, knowing that when one does become available, this has meant there are losses for other families. We hope that in some small way we can help those whose situation has required that Brummitt-Feasby House becomes their home.

We hope that over the summer months you will enjoy the events planned, knowing that you are helping those living with ALS – and for us we look forward to seeing you and sharing stories of hope, courage and fun.

Diana Rasmussen



PRESIDENT'S MESSAGE

Here we are mid July and I'm happy to report that the ALS Society of Manitoba continues its momentum to build capacity and offer the very best in care and support to those, and their families, living with ALS.

The Society has had a tremendously busy few months and is continuing the many events and third party activities which have been most successful. The first Cornflower Gala was a huge success at the Aviation Museum and will be back again in 2011 - bigger and better than ever! This took a considerable amount of time and organization on the part of the Gala committee and staff of ALS MB, and I would like to commend them, and each and every one of you, for making this inaugural fundraiser such a wonderful event.

Walks, walks and more walks have been in motion. The Winnipeg Walk was bigger this year than any previous year. Thank you to all who have made these fund raisers so successful. Your donations and those of friends and families help immensely to make the lives of those living with ALS the best that it can be. The Walks in particular also fund efforts in research toward finding a cure and reinforce our mission of the ALS Society of Manitoba which is one of HOPE - where we Help Our People affected by ALS Everyway we can.

With the Offices of the Society in a new location on Madison Street, and increasing demands for services, the Board of Directors will be looking at ways to assist our already busy staff over the next few months. At our Annual General Meeting we brought two new members on to our Board and conducted business in an open and transparent manner so our clients, volunteers and staff understand our operations and can contribute toward its success. Our Volunteer Appreciation event was well attended and honored our volunteers for their services to the ALS Society of Manitoba over the past year.

I want to thank each and every one of you for everything you do. Through your support, ALS Manitoba has been able to, and will continue making lives better for those living with ALS.

Shannon Nickel



WINNIPEG WALK FOR ALS

Winnipeg, you have done it again. Last year's Winnipeg Walk for ALS was such a success we didn't think that there would be any way that we could top it. But, on an overcast day, at the end of a long, rainy week, with another major charity event going on in the same park, you did it. We are still counting both numbers of people in attendance, as well as pledges raised, but the early count has attendance well in excess of 700 people, not including the many volunteers, raising a staggering \$95,000 plus, with more money still coming in. This money will go towards providing support services for the more than 220 clients living with ALS in Manitoba and their families, as well as helping to find a cure for ALS.



Special guests at this year's Walk included Charleswood, St. James, Assiniboia MP Steven Fletcher; Healthy Living Minister Jim Rondeau; Provincial Liberal Leader Jon Gerrard; and St. Charles City Councilor Grant Nordman. Other special guests included emcee Mookie Wilson of QX104; piper Gary MacDonald of MacDon Industries; The Manitoba Pan Handlers steel drum band; GoodLife Fitness; Dan the Magic Man; Lionel, the Boston Pizza mascot; the Green Drop mascot; Go-To the Safety Services mascot; and the MTS Clowns.



Thank you all. We look forward to seeing you all again next year and setting a new record for 2011. Our plan and focus at the ALS Society of Manitoba is to make our jobs obsolete by making ALS obsolete. Lets all work together to find a cure for ALS and make that plan a success.

Congratulations to Nancy McRae who won the Barbecue draw.

CHILDREN SUPPORTING THE WALKS

Tia & Katie's Garage Sale

Whitemouth Manitoba not only holds a Walk for ALS every year, they now can boast a very successful Garage Sale for ALS. This fundraiser, planned and executed by seven year old Katie, and her older sister Tia is now into its second year. Last year, Katie had a dream of holding a fundraising Garage Sale in support of the ALS Society of Manitoba and in honour of her Grandpa Rick who is living with ALS.



The event turned out to be such a success that the girls decided to do it again. Well, to make a long story short, they did it again!!! This year's sale brought in an amazing \$1,631 which went towards the Whitemouth Walk for ALS. Congratulations Tia and Katie for a job very well done. We are both proud and grateful to you.

Strathmillan School

When Kaitlyn Cava's father, Brian Cava, was diagnosed with ALS, Kaitlyn went to her school and asked them to participate in the Winnipeg Walk for ALS. She and her teacher, Mr. Bychuk, began a fundraising campaign at the school. When Kaitlyn's father passed away, and she took some time off to grieve, the school didn't stop, but continued fundraising, and supported her at the Walk. In total, Strathmillan School raised \$1,370 for the Winnipeg Walk for ALS in under two weeks. On June 25, the ALS Society joined Kaitlyn in presenting a plaque to Strathmillan School to honour their achievement and in memory of Brian Cava. Congratulations and thank you to everyone who participated and supported Kaitlyn in this great fundraising effort.



WALK FOR ALS RURAL MANITOBA

Whitemouth Walk

On Friday, May 14 more than 300 people came to Whitemouth from far and wide for the first Manitoba Walk for ALS of the season. Gathered in the Whitemouth School Gym in anticipation of the Walk were not only its 200 plus students, but local residents of Whitemouth, people from the Whitemouth Personal Care home, and friends and family of Rick and Joan Fewster. With money still coming in, this year's total is, thus far, over \$10,000. Fantastic job guys, we're proud of you. Thanks to co-coordinators Rick & Joan Fewster and Jennifer Staerk, and to everyone else who helped, especially all the students of Whitemouth school who are so incredibly supportive every year. Thank you and keep up the great work.



Prawda Walk

On Tuesday, May 18, Reynolds Elementary School in Prawda held their Walk for ALS, which raised over \$1,200. A great accomplishment for a group consisting of a couple of dozen students, staff, and a few parents. Joan Fewster made the trip out, although Rick was unable to come, and was touched by the show of support and concern for Rick that these children displayed. These students really showed that their hearts were in the right place. Congratulations to all of you. You have much to be proud of.



Minnedosa Walk

2010 turned out to be another great year for the Walk for ALS in Minnedosa, with nearly 30 people coming out on May 31, and raising over \$2,100 towards helping to support people living with ALS in Manitoba. Minnedosa holds their Walk for ALS in memory of Eleanor Robinson who lost her battle with ALS last year. Thanks go out to Alice McInnes and Donna Hogg for coordinating the walk, to all of the volunteers that helped them put it together, to the management and staff of the Dairi Isle, to piper Dan Jardine and, of course, to everyone who participated in this year's walk. Great job all of you. See you all again next year.



Belmont & Area Walk

I think that Belmont Walk Coordinator Bertha Buote may have even surprised herself, because even though her intention was to have an increase over last year, the reality turned out to be a very pleasant surprise. This year's Belmont Walk for ALS, on June 5, brought out over 100 people and raised in excess of \$10,500, with more money still coming in. The Ninette Motor Hotel and Dunrea Hotel both held meat draws with the proceeds, totaling \$960, going to the Belmont Walk. Outstanding job Bertha, thanks to you, and to everyone who volunteered, donated, and participated in this event. Thank you also to Ed Torz for providing some of the pictures of the Walk.



Riverton Walk

On Sunday, June 20, Father's Day, more than 40 members of the town of Riverton Manitoba took time out of their day to Walk for ALS. Fathers, mothers, children, even dogs joined together with a common goal; to end ALS once and for all. This year's total, with more money still coming in, is over \$3,500. Great job Riverton. The ALS Society of Manitoba would like to thank local Walk Coordinator Kahleigh Olafson, Kaitlyn Johnson and everyone who supported this event by participating, volunteering, donating prizes, and of course for coming out to walk.



2009 – 2010 EVENTS

Lite Up a Life

The 2009-2010 Lite Up a Life was extremely successful once again, with donations to light the bulbs on the trees in front of Brummitt-Feasby House exceeding \$3,900. The lighting ceremony held on December 14th brought out CTV's Jordan Witzel, the Free Press' Jen Skerritt, MLA Sharon Blady, Healthy Living Minister Jim Rondeau, MP Steven Fletcher's assistant James White, and City Councillor Grant Nordman, as well as several members of the ALS MB Board of Directors. Thank you to everyone who help make this event continue to improve every year.



ALS Cornflower Gala

Our inaugural Cornflower Gala on March 20th, was a great success, with nearly 150 in attendance and raising over \$28,000. Everything from the entertainment provided by Neil Keep and Friends to the meal served by Manhattan Catering was very well appreciated. We had great prizes donated to all three auctions and Bill Knight did a wonderful job as auctioneer for the live auction. We look forward to repeating this signature event again next year. Thank you to all our sponsors, volunteers, committee members and everyone who helped make this event a success.



Open House

Our Open House was a great success. Many people came out to view our new location at 493 Madison Street, and brought their congratulations and good wishes. Special guests included Healthy Living Minister Jim Rondeau, Kirkfield MLA Sharon Blady, and even ELVIS (Nick Drobot) came out to join in our celebration. Everyone enjoyed a tour of our new offices, snacks, conversation, and a chance to view our new promotional videos provided by Tripwire Media. Thank you to everyone who helped us make this move a reality.



AGM– Volunteer Appreciation Evening

On Wednesday, June 23rd, the ALS Society of Manitoba held its Annual General Meeting, followed by our Volunteer Appreciation Evening. It was noted that the past fiscal year was a banner year for the ALS Society of Manitoba, in which we created a series of videos, and designed a new website, with the help of Tripwire Media Group. We also relocated to new offices at 493 Madison Street. Other highlights of the AGM were the election of two new board members, Kathy Cava and Janelle Bordass. Congratulations and welcome to our Board.

Our Volunteer Appreciation Evening included wine, cheese and snacks, as well as an awards ceremony and presentations of Thank You certificates. Live entertainment was provided by Erin Neill. Due to the increasing amount of dedicated volunteers, this year, for the first time, but hopefully not the last, we have divided the presentation of the Frank Edmonds Volunteer Award into categories. The Winnipeg recipient of the award was Kelsey (Derksen) Jackson, the Rural award went to Rick and Joan Fewster, accepted by their granddaughter Tia, and the Youth award was presented to Kaitlyn Cava. Congratulations to all our award winners, and thank you to all of our dedicated volunteers. You are all heroes in our eyes and without you we would not be able to continue providing support services to all the Manitobans living with the effects of ALS.



An Evening With The Goldeyes

On Thursday, June 24, the ALS Society of Manitoba and the Winnipeg Goldeyes once again presented An Evening With The Goldeyes at CanWest Park. Our information booth provided people with valuable information about ALS, the ALS Society of Manitoba, and our upcoming events. We also passed batting helmets through the stands for donations. Thank you to all of our volunteers who helped with this event, to the Winnipeg Goldeyes for inviting us to CanWest Park, and of course to all the generous people at the game. We look forward to continuing this event next year.



DOUG OAKLEY'S C2C4ALS TOUR GOES THROUGH WINNIPEG

Doug Oakley is a man on a mission. When he was diagnosed with ALS 18 months ago he decided to combine the thing he loved, riding his Harley, with doing something important, raising awareness and funding for ALS research and support services. Last year he traveled to the four corners of the United States. Doug had thought that would be the end, but his ALS is slow onset, so he has more time than he originally expected. "I thought last year would be the last time I rode a motorcycle. This is all bonus time."



So now Doug and his brother Trent are travelling across Canada from coast to coast, and on Monday, July 5 the ALS Society of Manitoba had the honour of hosting them at the Brummitt-Feasby ALS House. Doug is a remarkably humble man. "I'm not doing anything much. I'm just riding my bike." In spite of what he says though, what he is doing is quite remarkable. Not only is he raising awareness of ALS across Canada, the donations he receives go to ALS Canada for research and to his host provinces to help with client services. Doug also has a bigger plan though. He plans to create a respite home, a retreat in Cape Cod for people living with ALS. Doug calls it, "paying forward."

On Tuesday, July 6, Doug and Trent travelled over to Harley-Davidson Winnipeg at 1377 Niakwa Road where Harley-Davidson owner, Sheryl Gray, and ALS Manitoba Executive Director, Diana Rasmussen, gave them a warm welcome. After an Honour Guard ride around the neighbourhood, Doug and Trent were back on the road for the next leg of their journey. Thank you very much for stopping in gentlemen, and best of luck on the rest of your ride. Stay safe.



THIRD PARTY EVENTS

Fishing for ALS

In February 2008, Paul Duncan from Derksen Plumbing and Heating Special Projects decided that the Derksen Group would host a Fishing Derby for their employees. It turned into a fundraising day for the ALS Society of Manitoba, in memory of Henry Derksen, who passed away from ALS. The Derksen Group Employees raised \$500 for ALS. This has become an annual event for the Derksen Group and to date has donated over \$3,100 to the ALS Society of Manitoba. Not bad for a little Fishing Derby. Thank you to Paul Duncan and all who have made these donations possible.



Playing for a Reason

Brent Strachan's Hamiota Senior Men's Curling Team wear a shoulder patches that say "In Support of ALS Research" to remind them that there are tougher things than a curling game. They have been wearing them ever since Brent's brother Dallas was stricken with the disease, and since then they donated a \$50 bill to the ALS for every game they won in Brandon. They also challenged their opponents to contribute \$50 if they beat the Strachan rink.



When the Hamiota Hockey Alumni found out about this fundraiser, they dedicated a game to Playing for a Reason and joined in the fundraising. Together the two fundraisers made a grand total of \$17,392. Congratulations and thank you from all of us at the ALS Society.



Dining for ALS at The Maple Tree

The Maple Tree Restaurant in Selkirk held an ALS Fundraiser in honour and in memory of Ken Maxim. This event, attended by 49 people, raised \$4,935 for the ALS Society. Thank you to everyone who helped make this fundraiser a reality.



DIGNITY IN CARE

An opportunity to participate in a Research Study finding out what affects a person's sense of dignity

The purpose of this study is to learn more about what affects a person's sense of dignity when they are living with a chronic medical illness such as ALS. The researchers want to learn more about what helps, or takes away a person's sense of dignity. What they find out from this study will help improve the way people are cared for.

Dr. Harvey M. Chochinov, from the University of Manitoba, is the Principal Investigator for this study. This is not a medication or treatment study. The study is taking place here in Winnipeg and in Edmonton, Alberta. It is hoped that 100 people with ALS will take part in the study.

If you are interested in hearing more about this study, contact either the research nurse, Katherine Cullihall, at 204-787-4924 {kathy.cullihall@cancercare.mb.ca} or Diana Rasmussen, Client Services Coordinator at 204-837-1291 {drasmussen@alsmb.ca}.

The ALS Society of Manitoba was founded in 1980 for persons with ALS, their families, friends, and other interested parties. During the past 30 years, the Society has helped clients and their families by providing information and support. As the 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. Our mandate is to make a difference in the lives of those living with ALS everyday.

Our mission is one of **HOPE** – to **Help Our People Every** way we can.

We are committed to providing support to ALS clients, their families, and caregivers through our programs. We are also committed to supporting research looking at the cause of and cure for ALS.

You can contact the ALS Society with any comments or questions by e-mailing **HOPE@alsmb.ca** or by calling **831-1510**.

ATTENTION – IMPORTANT NOTICE

It has come to our attention that a person or persons has been making phone calls soliciting for donations in the name of the ALS Society of Manitoba.

PLEASE BE ADVISED that the ALS Society of Manitoba DOES NOT and WILL NOT:

- 1. Engage in telephone solicitation for donations**
- 2. Door to door campaigns**
- 3. E-mail donation requests – with the exception of the request included in this newsletter**

If you experience any of the above please contact us immediately at 831-1510 or call the Winnipeg Police

UPCOMING EVENTS

JULY – OCT. - THE GREAT DINING EXPERIENCE RAFFLE

Now is your chance to experience some of the finest tastes of Winnipeg. Whether it's Restaurant Dubrovnik, The Gates, Amici, Rae & Jerry's or Step'n Out, if you like good food, you'll love this raffle. Tickets are limited so get yours today. Draw date, November 8, 2010.



AUG. 28th - ALS YARD SALE

One day only at Gloria Dei Lutheran Church. This year's Yard Sale will have something for everyone. Including: Furniture, Books, China, Glassware, Sporting goods, LPs, and much, much more. All profits will go to support Brummitt-Feasby ALS House. Please contact us if you have items to donate.



SEPT. 9th - 7th Annual DRIVE FOR LIFE GOLF CLASSIC

In memory of Marcel Bertrand. Join us at Bel Acres Golf & Country Club for a day on the links in support of the ALS Society – Lunch 11:30 – Texas Scramble Tee off 1:00 P.M. - \$200 per person (receive a \$100 tax receipt) Only 144 spots open. Help us to Drive Out ALS



SEPT. 24th - ELVIS, ONE NIGHT WITH YOU

If you Can't Help Falling in Love with ELVIS this show will have you All Shook Up. This isn't a Devil in Disguise, it's Nick Drobot performing a tribute to The King His Way. Don't be Lonesome Tonight, It's Now or Never, put on your Blue Suede Shoes, get your Little Sister, your Hound Dog, and even your Teddy Bear and join us at Delta Winnipeg for an evening of dancing to 50s & 60s music provided by Aime's Music Services, Elvis and Memphis themed snacks, "The Colonel's" Auction of HOPE, and two performances by Nick Drobot "aka" ELVIS. Tickets only \$50(\$25 tax receipt.)



NOV. 5th - 5TH CONFERENCE ON ALS

Join us at the Life and Learning Centre of Deer Lodge Centre for an educational and informative day of discussion about what is going on in the world of ALS. This event is for anyone living with ALS, their families, Health Care Professionals, and for anyone who would like to know more about ALS / Lou Gehrig's Disease. Registration \$85.



For information about any of the above events please contact:

Brian – 837-1270 e-mail: bcampbell@alsmb.ca

Sharon – 831-1510 e-mail: HOPE@alsmb.ca

MAKE A DIFFERENCE – GIVE HOPE IN ALS

Dear Friends,

Who do you turn to when all hope seems gone and your world starts to crumble around you? When my wife, Joan and I sat in the neurologist's office 2 ½ years ago and received my diagnosis of limb onset ALS that is exactly how we felt!

What do you do next? Who can you talk to? What are we facing? What equipment will we need? And a thousand other questions. We owe an eternal debt to the ALS Society of MB. We were fortunate enough to be in touch with them right from diagnosis.

Not only did they answer our questions they immediately put in place a plan for my visiting the ALS clinic and getting us involved in support groups, ALS Education Conferences, providing educational material, as well as helping us with the endless supply of equipment that we would need to have access to in order to cope with the disease as it progressed. Within months I went from using only a cane to needing a walker, manual wheelchair, scooter, power wheelchair, shower commode chair, Hoyer lift, hospital bed, bipap machine, feeding tube and on and on.

The MB ALS Society helped us through the maze of how to source these various pieces of equipment often supplying it to us from their loan closet when no other source was available. As important as the equipment has been their advice and counsel was even more important. The ALS Society of MB is only a phone call away with answers to the endless stream of questions that confront a person living with ALS.

In our darkest moments and at my most vulnerable and helpless stage of life they were there. **PLEASE** give what you can to help the ALS Society of MB help others living with ALS like Joan and I.

Thank you

Rick and Joan Fewster - Living with ALS!

Yes, I would like to make a donation in the amount of _____ (amount)

Your donation will be helping people living with ALS.

Enclosed is m: _____ Cheque _____ Visa _____ MasterCard

Card number: _____ Exp Date: _____

Name: _____

Address: _____

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Signature: _____ Date: _____

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Respiratory Care Group



SENTINEL SELF-STORAGE



If for some reason we have missed your name, we sincerely apologize. Please notify us at 831-1510 and we will make sure that you are in the next issue