



# ***Newsletter***

## ***Winter 2008***

### ***HIGHLIGHTS***

***Walk for ALS***  
***Ron Melnichuk Half Marathon***  
***Drive For Life***  
***ELVIS on the RED***  
***& More***



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ALS SLA

ALS SOCIETY OF MANITOBA  
LA SOCIÉTÉ MANITOBIENNE DE LA SLA

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## Mission Statement

Because **HOPE** is important in the lives of those impacted by ALS, we  
**H**elp **O**ur **P**eople affected by ALS **E**very way we can

## EXECUTIVE DIRECTOR'S DIARY

As winter approaches, our thoughts turn to crisp cold days, snow, and daytime getting shorter. Then all the hustle and bustle of the X-mas season is upon us and the days start to get longer again. We can look forward to all these events, but for Manitobans living with ALS and their families, their quality of life is determined on a day to day basis, and this is the most important thing to them.



All the activities of daily living we take for granted, from getting out of bed, washing, dressing, eating, drinking, brushing teeth, hugging and kissing, even laughing and much more, become in many ways a struggle – a struggle that sometimes is insurmountable.

I have had the privilege to meet many of our clients and families and work to assist you, but there is more to do.

Brummitt-Feasby ALS House, Manitoba's home with care and support for people living with ALS is the only home of its kind in North America. It continues to provide an alternative, home-like environment for those needing long term care and respite. This home provides a home away from home for Manitobans with ALS and our excellent staff make every attempt to make each day the best that it can be and enhance the quality of life for our clients.

We continue to raise funds to support our programs and research into a cure for this devastating disease. With new research on the horizon and increased programming for clients, and through your support, I know that 2009 will be a great year.

Seasons Greetings to all and good wishes for 2009.

Diana Rasmussen

## PRESIDENT'S MESSAGE

I am extremely proud of the work that the ALS Society of Manitoba does on behalf of people with ALS in Manitoba and my sincere thanks go our dedicated and hard working staff at our office and at the Brummitt-Feasby ALS House. The Board of Directors takes its role and responsibilities very seriously and is committed to continuing to provide quality programs and services to Manitobans with ALS.



This year, many Manitobans lost their battle to ALS. At the same time, many more Manitobans were diagnosed with ALS and now face their own battle.

The ALS Society of Manitoba is here to help make sure people with ALS and their families' get assistance to make their quality of life better while they fight their battle. In 2008, the ALS Society of Manitoba has loaned over 200 pieces of equipment to Manitobans with ALS. We have also provided support, counseling, education, books and videos to help Manitobans affected by ALS. We've continued our bursary program for children, youth and young adults affected by the diagnosis of a parent or family member with ALS. We have matched volunteers to clients and families in our Volunteer Family Advocate Friend program, and much, much more.

None of the programs can take place without the support of our volunteers, sponsors, families, friends and our clients. I want to take this opportunity to thank each and every one of you who has assisted us in 2008. Your contribution makes our programs a success and supports our Mission of HOPE – Helping Our People with ALS Every way we can.

From the ALS Society of Manitoba's Board of Directors, all the best this holiday season and in 2009!

Lanny McInnes

# WINNIPEG WALK FOR ALS



The 2008 Winnipeg Walk for ALS, held on Saturday, June 14 was tremendously successful, involving more than 300 combined walkers and volunteers. While registering, everyone either ate some of the pre-walk snacks, watched clowns make balloon animals, got their faces painted, bought tickets for the silent auction or just enjoyed the opportunity to mix and mingle. Special guests included, VIPs, the Honourable Steven Fletcher,



Assiniboia MLA Jim Rondeau, Deputy Mayor Brenda Liepsic, and Manitoba Liberal leader Dr. Jon Gerrard. Goldie from the Goldeyes and Buzz and Boomer from the Bombers also made guest appearances.



After speeches by Executive Director, Diana Rasmussen, ALS Manitoba President Lanny McInnes, and the VIPs, the walkers started on their way, sent off to the music of a bag piper, and a little assistance by Goldie.

They returned to lunch served by Manitoba Pork and an ALS cake for dessert. While people enjoyed their lunches, the silent auction draws were made. Almost on cue, Mother Nature signalled the end of the event by finally sending the rain that had been holding off up until that point. Walkers and volunteers alike, gathered their belongings and headed for home, all prepared to come back and do it again in 2009. The ALS Society of Manitoba would like to thank everyone who made this event possible, and we hope to see you all again next year.

Lets continue to work together to **Help Our People** Every way we can.

Brian Campbell



# WALK FOR ALS – RURAL MANITOBA

Another successful year for all our Rural Manitoba Walks. This year we had a total of 4 Rural Walks including two new locations. Unfortunately we were not able to have a Walk in Neepawa, MacGregor, Selkirk or Thompson due to numerous different reasons; however thanks to Lorraine Forester as well as Rick and Joan Fewster, we had two new locations added; Reynolds School and Whitemouth.

**BELMONT** – Coordinator Bertha Buote – 56 Participants raising \$8,928.00 – The Top Fundraiser in Belmont was Clara Myers



**MINNEDOSA** – Coordinators Alice McInnes and Donna Hogg – 55 Participants raising \$2,802.00 – The Top Fundraiser in Minnedosa was Tess Meadows



**REYNOLDS SCHOOL** – Coordinator Percy Koehler – 32 Participants (most under 10 years of age) raising \$1,202.00 – The Top Fundraiser in Reynolds was Lorraine Forester



**WHITEMOUTH** – Coordinator Jennifer Staerk – 71 Participants raising \$12,419.00 – Top Fundraiser in Whitemouth was Kent Creiton



Sharon Carter

**URGENTLY NEEDED** - The ALS Society of Manitoba is presently looking for Volunteer Walk Coordinators for the following locations. Neepawa/Gladstone area, Steinbach area, Morden/Winkler area and Brandon The Volunteer Walk Coordinator would work closely with the ALS Society of Manitoba office Staff and would be responsible for getting a Walk Location and date, arranging for events for the day of the Walk, distributing posters and pledge forms as well as garnering relationships with local businesses. If you would like to help the Society to increase both funding and awareness and would like to help organize a Walk in your area, please contact Diana Rasmussen at 837-1291 or email [drasmussen@deerlodge.mb.ca](mailto:drasmussen@deerlodge.mb.ca).

# RON MELNICHUK HALF MARATHON AND 5K RUN/WALK

Over 200 combined participants and volunteers showed up first thing Sunday morning on August 17 for the Ron Melnichuk Half Marathon and 5K Run/Walk in support of the ALS Society on Manitoba. The Half Marathon's 127 participants started their run promptly at 8:00 a.m., with the 5K beginning fifteen minutes later.



Sam Zhou was the first man to cross the half marathon finish line with a time of one hour and 19.10 minutes. Michael Terepa was the second man across the finish line. Audrey Goertzen was first among the women, running one hour 33.44 minutes. Gina Tessmann was the second woman across the finish line.

Gord Steeves was the leader in the 5K run, with Jencho De Castro and Leyton Roe coming in second and third respectively. Lindsey Carroll was the first woman across the finish line in the 5K.

The weather was great for going to the beach, but a bit too hot and muggy for a half marathon, but the runners handled the heat with minimal complaint, although many were happy to see both the water stations and the finish lines. All enjoyed the fruit, bagels and Gatorade waiting for them when the run was over and relaxed as the awards were given out.



The success of the 2008 Ron Melnichuk Half Marathon & 5K Run for the ALS Society is a sure sign of better things to come and plans are already underway to make it even better next year. Whether you are a marathoner, a jogger, a walker or a watcher, come out and join us at Bird's Hill Park for next year's Ron Melnichuk Half Marathon. We look forward to seeing you.

Brian Campbell



# THE 5<sup>TH</sup> ANNUAL DRIVE FOR LIFE GOLF CLASSIC

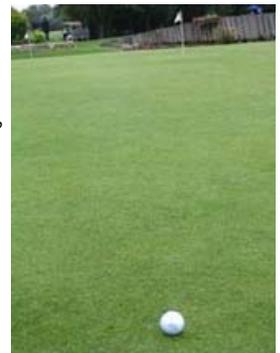
On Thursday, September 4th the weather was cool, with dark clouds threatening overhead, which occasionally sent down spatterings of rain. Not the ideal day for the 5<sup>th</sup> Annual Drive for Life Golf Classic for the ALS Society at Bel Acres Golf & Country Club.



But the golfers creed is that a bad day on the course is better than a good day in the office, and the 127 players who came out apparently believed this, because they were out to have fun in spite of the weather. In this, they were successful, and weather notwithstanding, a good time was had by all.



After registration and lunch by Boston Pizza, the shotgun start for the Texas Scramble was underway. Along with the regular golf game, there were also a number of contests provided by various sponsors, and a putting contest put on by the ALS Society.



After the tournament everyone relaxed and enjoyed the banquet dinner and awards ceremony, emceed by Clear 102's Jay and Billie Jo. The championship team for the 2008 Drive for Life Golf Classic was Apex Distribution. The winner of the ALS putting contest was Ernie Wilson, with Rick Woodward of Apex coming in second. Among other prize winners, Clear 102's Billie Jo Ross won the longest drive contest among the women.

Plans are already underway for next year's Drive for Life Golf Classic and we look forward to making it even bigger and better. So whether you are a seasoned pro or just a hacker, get a team together and join us on the links at Bel Acres Golf and Country Club. Enjoy a day on the course while helping out a worthy cause.

**Help us to Drive out ALS.**

Brian Campbell



# ELVIS ON THE RED

The entire audience aboard the Paddlewheel Queen couldn't help falling in love with ELVIS on Friday, September 19, as Nick Drobot performed his tribute to the King in support of the ALS Society. The cruise ran from 7:00 until 11:00 and started with a wonderful dinner provided by the staff of Paddlewheel Cruises.

Then the moment everyone was waiting for, ELVIS (Nick) took the stage for his first set. Within moments he owned the crowd. Side talk all but disappeared and all eyes in the place followed his every move. The boat had gone back through time. Elvis was back, and as good as ever. The only



additional sound on the boat came from people singing or clapping in time to the King. Over the next hour, Nick led us through Elvis' legendary song list, from All Shook Up to Hound Dog; Are You Lonesome Tonight to Heartbreak Hotel. About halfway through his set, the song Little Sister announced the entry of some back up dancers, led by Nick's Priscilla (his wife Colleen) and some of her sisters and family members. Songs like Blue Hawaii and Teddy Bear provided ELVIS with the opportunity to come out into the crowd to hand out leis and teddy bears, often pausing for hugs and pictures.

Even the break wasn't actually a break for ELVIS, since he spent the duration of it visiting with his many fans, chatting, signing autographs and getting pictures taken. In fact, he was having such a good time visiting with everyone that it was difficult to get him back to the stage for his second set. And what a



second set it was. Nick hadn't slowed down one bit. In fact, if anything, he was much more pumped up and ready to give everyone their money's worth. From Can't Help Falling in Love, sung directly to ALS Manitoba board member Kathleen Kirk, to Viva Las Vegas, which inspired a Priscilla led conga line, the second set was even more highly charged than the first. Even after he was finished singing, his show wasn't over, since he made sure to wish everyone well individually as they left the boat.



From beginning to end, Nick Drobot was a class act, and put on a tribute to Elvis that no one will soon forget. The ALS Society will certainly not forget it, and plans are already in the works to do it again next year. Watch for your chance to get tickets to this incredible show.



Brian Campbell

# 3RD ANNUAL CONFERENCE ON ALS



The Life & Learning Centre at Deer Lodge Centre was the site of the 3rd. Annual Conference on ALS, hosted by the ALS Society of Manitoba. Attendees to the Conference included health care professionals, ALS Manitoba members as well as families and friends of those affected by ALS. There were displays provided for viewing by the ALS Society, Hospice Palliative Care and Drake Medox Health Services.

After a light breakfast, the conference began with welcome speeches from Lanny McInnes, President of the ALS Society of Manitoba and Dr. Denise Figlewicz, Director of Research of the ALS Society of Canada. Dr. Alan Casey, Director of Manitoba's ALS MND Clinic, explained what is happening in the clinic, what their needs and challenges are, and what they are doing to help people diagnosed with ALS and Motor Neuron Disease.



Jiming Kong, the Associate Professor at the Department of Human Anatomy and Cell Science Researcher at the University of Manitoba discussed advances in ALS research and what is being done towards finding the cause and hopefully a cure for ALS. Dr. Denise Figlewicz spoke about what is happening in ALS Canada, and the human aspects of the condition.

The conference took a brief lunch break, which gave people a chance to talk, look at the exhibits or buy ALS Society souvenirs. After the break, the next speaker was Arthur Schafer the Director of the Centre for Professional and Applied Ethics at the University of Manitoba, who spoke about choices and decision making for people with ALS, and particularly on the delicate subject of assisted suicide. Following Professor Schafer was a panel discussion made up of ALS Manitoba Executive Director/Client Services Coordinator Diana Rasmussen, Home Care Coordinator for ALS Clients Sue Erickson, ALS Board member and member with ALS Kathleen Kirk, and Rick and Joan Fewster, a couple living with the effects of Rick's ALS.



They each took a turn telling about themselves and how ALS is affecting their lives, then opened the floor to questions.



In closing ALS Manitoba Executive Director/Client Services Coordinator Diana Rasmussen discussed the needs of the ALS Society and what people can do to help. The day ended with thank you's to all involved and a request to fill out the evaluation

cards on the tables. In all, the conference went a long way towards educating people, not only about ALS, but about what is happening in the ALS Society and what is being done to help people affected by ALS. Since knowledge is power, the best way to fight a disease as devastating as ALS is to know as much about it as possible. The ALS Conference is a tremendous resource in getting this knowledge to the people who can best use it. Watch for the 4th Conference on ALS next year.

# A NIGHT OUT AT CHARISMA OF INDIA

For the more than 70 people who attended A Night Out at Charisma of India in support of the ALS Society of Manitoba there is only one question. What was the highlight of the evening? Was it the amazing East Indian food served up by Mitesh and his staff? People were drawn to the buffet line by the savoury smells alone. Many were drawn back for seconds, and even thirds, after tasting the food. The selection provided all with a mouth watering example of the very best in East Indian cooking. Or was it the entertainment? As people were relaxing and happily digesting their meals, the Turkish Taffy Belly



Dancers took the stage, and treated everyone's eyes with an incredible show of belly dancing. After showing the audience the many variations of belly dance, from the hypnotic to the dizzying, the dancers invited many of the audience up to help break in Charisma of India's new dance floor.

It may be difficult to say what the highlight was, but one thing is certain, the evening will not be soon forgotten by everyone who attended. In fact, it was so well appreciated, that plans are already in the works to repeat it. Watch for the next Night Out on January 26, 2009.



Brian Campbell

## UPCOMING ALS MANITOBA EVENTS

**Call the office at 831-1510 for information about these or other ALS Society of Manitoba Events**

### *CHRISTMAS TEA, BAKE SALE & AUCTION:*



Saturday, December 6, 2008 1:00 P.M. – 4:00 P.M.  
Gloria Dei Lutheran Church, 637 Buckingham Road  
\$8.00 per person—advance—\$10.00 per person at the door  
Tea—Sandwiches—Dainties—Door Prize

### *LITE UP A LIFE:*



Help to Lite the Bulbs On the trees in the front yard of the Brummitt-Feasby ALS House throughout the months of December and January —3 Bulbs for \$5 or 7 Bulbs for \$10 (Any donation of \$10 or more will receive a tax receipt) All Proceeds Support Client Programs at Brummitt-Feasby ALS House  
Help To Lite Up A Life Now and in the Future

### *A NIGHT OUT AT CHARISMA OF INDIA:*



January 26, 2009 Charisma of India will once again be hosting an evening of East Indian food at its finest—Turkish Taffy Belly Dancers will be providing the entertainment

*WATCH FOR TWO MORE ALS SOCIETY OF MANITOBA EVENTS COMING THIS SPRING*

# WHAT WOULD YOU DO IF YOU STILL COULD

Dear Friends,

We need your help – Imagine not being able to move or speak, hugging a loved one or giving a kiss to a new baby or family member!! Your mind knows what it wants but the body won't do it!!!!!!!!!!!!

ALS, commonly known as Lou Gehrig's Disease is a devastating diagnosis to be given. With no known cause or cure, people with ALS need **HOPE**. We must find a cure and soon. This fatal neuromuscular disease knows no boundaries and affects both men and women – young and old alike.

One thing we do know is that more people in our province are being affected with ALS – numbers are steadily increasing... With a lifespan of 2 – 5 years or less and a little longer if you are lucky –

**What Would You Do If You Still Could!!!!!!**

Your support will assist us in helping Manitobans with ALS by providing equipment they need, providing education and counseling, support for families, special programs for children and much, much more. Most importantly, your donations will make a difference for those living with this terrible disease.

Donations of \$20.00 or more will receive a tax receipt. As a small charity and in this time of economic restraint we are asking for your help for those with ALS.

Your assistance is greatly appreciated and will support Manitobans battling ALS.

**Please give what you can.**

**MAKE A DIFFERENCE AND GIVE SO OTHERS MAY LIVE**

Happy Holidays to all and good wishes for 2009.

Thank you

Diana Rasmussen  
Executive Director

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: \_\_\_\_\_

City: \_\_\_\_\_ Province: \_\_\_\_\_ Postal Code: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**Registered Charitable Number: 120654421RR0001**

# Thank You to all the Event Sponsors of the ALS Society of Manitoba



- |                                     |                                   |                              |
|-------------------------------------|-----------------------------------|------------------------------|
| A & W                               | Fountain Tire                     | Murray Chev Hummer           |
| Advance TV                          | Framing & Art Centre              | Novopharm                    |
| Airmovement                         | Fred Albi                         | Pepsi Bottling Company       |
| All City Exteriors                  | Gags Unlimited                    | Powerland Computers          |
| AM Coffee Services Inc.             | Gasthaus Gutenberger              | Prairie Theatre Exchange     |
| Apex Distribution Inc.              | Giselle's Professional Skin Care  | Procurity                    |
| Bel Acres Golf & Country Club       | Gloria Dei Lutheran Church        | Quiznos                      |
| Birchwood Automotive                | Golden Tan                        | Rae & Jerry's                |
| Bothwell Cheese                     | Golf Town                         | Reflections                  |
| Brian and Linda Fulmore             | Good Life Fitness Clubs           | River Oaks Golf Course       |
| CAA Manitoba                        | Grapes Restaurants                | Roblyn United Church         |
| CAF—17 Wing Winnipeg                | Griffin Canada                    | Royal Bank of Canada         |
| Calabria Market                     | GRP Media Services                | R U Better                   |
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| Canada Safeway                      | Harvest Bakery                    | Scott Bakery                 |
| Carol Abbott                        | Holiday Inn Winnipeg Airport West | Sepoy Wong                   |
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| Charleswood United Church           | Hydron-Aire Ltd.                  | Sobeys                       |
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| Construction Labour Relations       | Karmain West                      | Star Books                   |
| Costco                              | Kenaston Wine Market              | Starbucks                    |
| Country Inn & Suites                | King's Florist                    | Steinbach Credit Union       |
| Crosstown Civic Credit Union        | Kite and Kaboodle                 | Stewart Trophies & Engraving |
| Danny's Whole Hog BBQ               | Krevco                            | St. James Lanes              |
| Deb Bratanic                        | Labatts Manitoba                  | Subway                       |
| Denny's                             | Lacosta                           | The Cupcakery                |
| Diamond Athletics                   | Lorette Golf Course               | The Keg                      |
| Diggers Antiques & Collectibles     | Manitoba Lotteries                | The Shoe Guy                 |
| Dollar Thrifty Truck Rentals        | Manitoba Museum                   | Thomas Steen                 |
| Dutch Meat Market                   | Manitoba Opera                    | Tinkertown                   |
| Eatz Enterprises (Moxie's)          | Manitoba Public Insurance         | True North Entertainment     |
| Edward Carriere Salons              | Marigold                          | United Rental                |
| E.H Price                           | Marika Barchuk                    | Valour Decorating            |
| Eyelet Dove                         | McNaught                          | Wal-Mart                     |
| Fabutan                             | McSweeney                         | Webber Company               |
| Finales                             | Movie Gallery                     | Wendy's                      |
| Folk Arts Council of Winnipeg Inc.  | Movie Village                     | Winnipeg Blue Bombers        |
| Fort Garry Breweries                | Mr. D's Tart 'N' Pie              | Winnipeg Symphony Orchestra  |

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