

# ***Newsletter***

## ***Winter 2011/2012***

*All the best of the Winter Season*

*from the staff and board of the*

*ALS Society of Manitoba*

ALS Society of Manitoba  
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[www.alsmb.ca](http://www.alsmb.ca)

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## EXECUTIVE DIRECTOR'S DIARY

This issue of the newsletter brings with it the thoughts of colder temperatures, snow and outdoor activities. We are through the holiday season and yet the temperatures have been more like fall. But like many things winter can bring the blues and some people do not function well when it is colder and also getting out and about can be more challenging. This is even more so when you are care giving for a family member with ALS. Responsibilities can be a heavy burden.

So take a deep breath, think about your own health and how much energy you have. You may have to prioritize tasks. Some family members may not always be able to step up and provide the back up that you need, so sometimes we have to look at alternatives. Perhaps you may need some help. Have you thought about what you need? Do you need home care, respite, a friendly visitor or do you need someone to help you with some odd jobs that you just find hard to do? Make a list. When care giving it is easy to get caught up in all the tasks and forget yourself. Make time for you, pick up the phone and reach out. Call the friend that perhaps you have not spoken to for a while. Care giving can be rewarding, but you need to be willing to listen and care about yourself. Our loved ones are important to us. If we stay mentally and physically healthy care giving will not be such a daunting task. As we transition through 2012 we have much to do to support our Clients and families living with ALS - please call if you need our help.

Our program and services continue and to support our programs we must fundraise. Thank you to all the sponsors, donors, supporters, friends, families and clients who help us in so many ways. Please feel free to let us know how we can serve you better.

Lets make 2012 a banner year, helping our clients/families and create more awareness. Let us also continue to support research to find a cause for ALS and also a Cure.

Diana Rasmussen  
Executive Director/Client Services Coordinator



## PRESIDENT'S REPORT

2011 was a busy and eventful year for the ALS Society of Manitoba. The number of individuals with ALS in Manitoba continues to grow, especially in the rural areas. Currently there are over 260 individuals living with ALS in Manitoba compared to 160 just five years ago. This rapid increase has put significant pressure on the Society to be able to provide the necessary services and support to clients and their families. Thankfully our donors also continue to grow and I would like to thank all the individuals and businesses who support us, especially our loyal contributors who continue to be there year after year.

Financially, 2011 was another successful year. Funds raised from our Walks for ALS in 2011 increased 50% over the prior year and we want to continue to grow the participation in this event. I would like to thank the volunteers who organize all our Walks throughout Manitoba as well as the participants who make them such a success. We were pleased to have the support of new walks in the Cypress River, Glenboro and Notre Dame areas in 2011 and hopefully 2012 will bring us new walks and increased participation.

In August we added a full time client coordinator position to our staff. This has been a goal of the Board for the last several years as the number of individuals living with ALS in Manitoba continues to grow. We were also in the position to increase our equipment program funding this year.

At our AGM in June 2011, all of our Director positions were filled. I would like to thank our returning Directors and welcome our seven new Directors. We held a successful strategic planning session in late November and are currently finalizing our strategic plan for the next three years.

I would like to thank the Staff, Volunteers and the Board of Directors for their dedication and commitment. It is tremendous to see the growth of the Society over the last five years and although we have been able to increase the support provided to individuals living with ALS and their families and the amount contributed to research over the last few years, there is still a lot more support to be provided and a cure to be found and we need your help to do it!

Lorna McLeod  
President  
ALS Society of Manitoba

# CAREGIVER STRESS

## **Question - Are you caring for someone with ALS or providing care??**

Taking care of anyone who is ill for a lengthy period of time is always difficult and that can also be said when caring for someone with ALS.

Looking after someone you love at any age, caregiving can be hard. We all hope that we will be able to keep our own health, but sometimes we get run down also.

So looking after yourself is a key factor.

Knowing and recognizing the signs of stress in yourself is the first step in taking action.

We know that there are long term emotional and physical tolls in caregiving, understanding the common signs of caregiver stress will give you a head start to helping yourself, however if you experience a number of these symptoms on a regular basis please seek help and call your doctor or the ALS Society of Manitoba for help.

## **Symptoms**

Denial.....about ALS and its effect on the person living with ALS, thinking that the disease will go away.

Anger..... at the person with ALS as their needs increase and you have to do more.

Withdrawing Socially.....not wanting to stay in touch with people you know, or going out with friends socially, not wanting people to see you as your conditions change.

Anxiety.....What will another day hold, what about the future, what if I cannot manage physically, emotionally and financially.

Depression.....felling sad, hopeless, not caring about yourself.

Exhaustion.....you don't have the energy to do anything, even day to day activities.

Sleeplessness..... You feel tired , you may wake up in the night, or have bad dreams, your constantly listening and wondering if your loved one is OK.

Emotional Reactions..... You feel like crying even at little things, you sometimes get irritable, you may even yell at someone, which may not be in your nature.

Lack of concentration..... You find it difficult to focus and complete tasks.

Health Problems.....you may lose weight or gain weight, you may have gotten sick more often, things like colds and flu, backaches, headaches

If you appear to be experiencing any of these symptoms and you feel like you are having difficulty coping, we are here to help you.

Feel free to contact us at ALS Society of Manitoba 837 1291, you don't have to experience this alone!!!!

# 2011 RESEARCH BREAKTHROUGHS

## July 2011 — Sanjay Kalra, MD, University of Alberta

Sanjay Kalra from University of Alberta's faculty of medicine and dentistry released two studies that used advanced imaging to show that ALS attacks multiple parts of the brain and is not limited, as previously assumed, to the motor system. Kalra used MRI scans to detect chemical changes that indicate specifically which neurons are not working or have died — a landmark breakthrough in our ability to identify the locus, onset, and ontology of the disease. These advances have significant potential to track ALS and its progression, enabling development of more targeted treatments to slow or prevent the disease in those parts of the brain which are affected beyond the motor system.

## September 2011 — Rosa Rademakers, PhD, Mayo Clinic Jacksonville

A team led by Rosa Rademakers identified the most common genetic cause known to date for ALS and frontotemporal dementia. Results show that a mutation of a single gene, called C9ORF72, accounts for nearly 50 per cent of the directly inherited familial ALS and frontotemporal dementia (FTD) in the Finnish population, and more than a third of familial ALS in other groups of European ancestry. Further studies by other groups have found mutations in this gene in individuals with sporadic (i.e., non-hereditary) ALS. Identifying this defective gene provides important insights into the complex interplay between genetic risk for the disorder and other factors which contribute to disease onset and progression. These insights pave the way for a better understanding of ALS and FTD biology and the therapeutics that can be developed to counteract it. University of British Columbia's Ian MacKenzie, MD, was a key Canadian contributor to the study.

## September 2011 — Neil Cashman, MD, University of British Columbia

In healthy individuals, special enzymes protect cells from dangerous free radicals. But malformed enzymes, such as those found in ALS, may have the opposite effect, in essence initiating damage rather than protecting against attack by dangerous free radicals, in a twisted game of molecular tag. Neil Cashman and colleagues at the University of British Columbia reported in 2011 on their use of a truncated enzyme and special antibodies to analyze the folding and misfolding of a key protein. The goal is to create new proteins with a special binding capacity to act as a "sticky patch" where "bad" enzymes can attach and be removed from the system. With further development, these proteins have the potential to block unhealthy interactions, thereby stopping disease progression in its tracks.

## November 2011— Jean-Pierre Julien, PhD, Université Laval

ALS is characterized by a degeneration of neurons that control muscle activity. By studying the spinal cords of people who died from ALS, Julien's team discovered an overproduction of a protein called TDP-43 in their nerve tissues. This protein can play a key role: when it is "overexpressed," it exaggerates the inflammatory response that increases the vulnerability of nerve cells to toxic molecules that circulate in the body. The team is testing an inhibitor that could lead to the development of drugs to reduce this inflammation and partially restore the neuromuscular function.



To find out more about these and other breakthroughs in ALS Research, go to the ALS Society of Canada website at

[www.als.ca](http://www.als.ca)

or

The Canadian ALS Research Network at

[www.alsnetwork.ca](http://www.alsnetwork.ca)

# 2011 EVENTS

## 2011 ALS Yard Sale

As it has in the past, the many generous donors once again grew this year's ALS Yard Sale on Saturday, August 27<sup>th</sup> to huge proportions filling up, not only the interior, but the parking lot of Gloria Dei Lutheran Church. On the day of the sale people lined up at the door and rushed en masse to grab up the bargains. This year's weather was perfect for yard saling, warm and sunny, and people took advantage of it throughout the day. Thank you to Sentinel Self Storage, Gloria Dei Lutheran Church, Kings Transfer, and all of our many volunteers who helped us haul, store, organize and sell everything prior to, during and even after the event. We appreciate all that you have done and continue to do to help support the ALS Society of Manitoba and the Brummitt-Feasby ALS House.



## 8th Annual Drive for Life Golf Classic

The ALS Society of Manitoba's 8th Annual Drive for Life Golf Classic in memory of Marcel Bertrand, held at Bel Acres Golf & Country Club on Thursday, September 8 was an overwhelming success. The weather couldn't have possibly been any better for a day on the links, hot, sunny and calm; and the full slate of golfers greatly enjoyed their afternoon on the course. Of course if your golf game was a little off, it didn't hurt that there were plenty of things going on at the holes; from food and drink samples, to many fun contests. Thank you to everyone who made this event possible; the sponsors, hole sponsors, prize donors, volunteers and, of course, all the golfers who came out to support us. A special thank you goes out to our emcee, CJOB's Greg Mackling, for keeping our evening dinner and festivities running smoothly. Thank you also to Bel Acres for once again hosting the event and not only providing a great course for our golf tournament, but our wonderful dinner afterwards. We look forward to seeing everyone again next year.



## ELVIS, One Night With You 2011

For the past four years, Nick Drobot has been bringing the spirit of Elvis to Winnipeg in support of the ALS Society of Manitoba. On Friday, September 23rd he rocked the Masonic Memorial Temple, with ELVIS, One Night With You. Those in attendance were treated to the best of Elvis with two 90 minute plus performances that included not only a stage performance, but personal visits from Elvis, as Nick and his assistant came down into the audience to hand out teddy bears, leis and scarves during various parts of the performance. The audience got into the spirit and were up dancing and even coming up on stage to collect scarves, hugs and kisses from "Elvis." The ALS Society of Manitoba would like to thank everyone who made this show possible; Stanroy Catering Services and the Masonic Memorial Temple for providing us with the venue and food, NCI Radio, CJOB Radio, Canstar News and Prime Times for their advertising support, our sponsors Zealous MediSpa and Tache Pharmacy, Aime's Music for working with Nick on the show and for providing between show music, and to all of our silent auction prize sponsors. We would also like to thank Nick for once again giving us an amazing performance. Thank you, thank you very much.



## Lite Up a Life 2011

On Wednesday, December 14, 2011, the ALS Society of Manitoba held the Lighting Ceremony for its annual Lite Up a Life event in support of the Brummitt-Feasby ALS House. A record number of people attended the event including local politicians, ALS Society of Manitoba staff and board members and family and friends of those affected by ALS. There were a number of heartfelt speeches given, and a cheque presentation by Dufresne Foundation, then everyone went outside to light up the trees in the front yard of Brummitt-Feasby House. This year, due to both the large amount of donations, and the large trees donated by Lacoste Garden Centre, the lights shone brighter than ever. ALS Client, Kathleen Kirk, led everyone in song, before we all retreated into Brummitt-Feasby House for coffee and treats. Thanks to everyone who donated to Lite Up a Life, we made over \$5,700 towards support services for the Brummitt-Feasby ALS House.

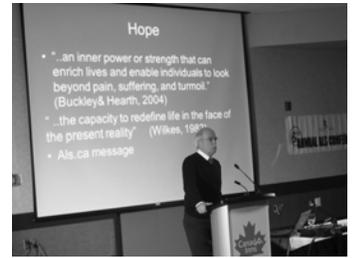


# 6TH ANNUAL CONFERENCE ON ALS

## 6<sup>th</sup> Annual Conference on ALS

On Friday, November 4, 2011, the ALS Society of Manitoba held its 6th Annual Conference on ALS at Canad Inns Polo Park, Winnipeg. The event was attended by health care professionals, as well as ALS clients, their families and caregivers who joined us from all over Manitoba. Guest speakers included Denise Figlewicz Ph.D, Vice President of Research ALS Canada; Dr. Colleen O'Connell MD FRCPC, Research Chief, Stan Cassidy Centre for Rehabilitation, New Brunswick; Fred Nelson MSW RSW,

Psychosocial Program Specialist WRHA Palliative Care Program; and a person living with ALS. The speakers talked about a variety of subjects including, Sexuality and ALS, ALS and our Veteran Population, Psychological and Emotional Issues, Research updates, and tips to make you safe and happy. Thank you to everyone who made this event possible. We especially thank our generous sponsors, Manitoba Hydro, MediChair, Northland Healthcare Products, Rana and WRHA. Thanks go out to Canad Inns Polo Park for their gracious hospitality and to Tripwire Media Group for video taping the speakers and producing the videos. Of course a huge thank you goes out to our speakers, our volunteers and to everyone who attended the event. We look forward to seeing you all again next year.



## THIRD PARTY EVENTS

### Third Party Golf Tournaments

This summer provided us with three wonderful third party Golf Tournaments, all of which were quite successful in providing both needed funding and awareness. The **Henry Derksen Memorial Golf Tournament** at Bel Acres Golf and Country Club, is an annual tournament in support of the ALS Society, the **Vipond Golf Tournament** at Larders at St. Andrews Golf and Country Club, is a company tournament that picked the ALS Society as their charity of choice and held a putting contest to help raise funds, and the **Rotary Club Charity Golf Tournament** at Breezy Bend Country Club is a new Tournament that selected Brummitt-Feasby ALS House as a charity that they wish to support. Thank you very much to everyone who helped organize, sponsor, donate and participate in all of these tournaments. Your support is gratefully appreciated and we look forward to partnering with you all again next year.



### The Masullo-Mirlycourtois ALS Dinner

This is now the third year for this gourmet dinner in support of the ALS Society of Manitoba and in honour of Chef Bernard and Carole Mirlycourtois. This year the dinner was an invitation only event, held at the St. Charles Country Club and run entirely by Chef Takashi Murakami. Chef Bernard was given the night off to sit and enjoy the meal with his beloved Carole. Thank you to all the chefs and everyone involved in making this amazing event happen. You have our deepest gratitude for your hard work and support.





## WOULD YOU LIKE TO BECOME A WALK FOR ALS COORDINATOR?

We need to expand our Walks and require Volunteer Walk Coordinators in other rural locations throughout Manitoba. Dedicated, organized individuals wishing to donate time towards managing a 5K Walk for ALS are needed. Please help us by starting a Walk in your area!

We are willing to offer training for those individuals who are interested, but not sure how to Coordinate a Walk in your community. Becoming a Walk for ALS Coordinator can help you develop and hone your management and organization skills. We would be happy to give you ideas and advice on how to host your own Walk, based upon many successful Walks throughout our province.

**If you are interested in coordinating a Walk in your area, or want training or information on how to host your own Walk, please call toll free :**

**1-866-718-1642, fax your resume to 1-204-837-9023 or e-mail it to [HOPE@alsmb.ca](mailto:HOPE@alsmb.ca)**

**WHAT WOULD YOU DO IF YOU STILL COULD?**

## UPCOMING EVENTS

Join the ALS SOCIETY OF MANITOBA for the

### *2012 Cornflower Gala*

Saturday, March 24

In the Hangar of the Western Canada Aviation Museum

5:30 pm Cocktails 6:30 pm Dinner

Fine Dining · Fundraising · Friendship

2012 Cornflower Gala Features:

Fine Dining Catered by Urban Prairie Cuisine

Live and Silent Auctions - Auctioneer: Adesa Public Auctions

Eight piece Dance Band: Mr. "E" & The Jazz Gumshoes

MC: Maralee Caruso

Evening Attire

Tickets: \$140.00 (Partial tax receipt)

For tickets or information call: (204) 831-1510

E-mail: [HOPE@alsmb.ca](mailto:HOPE@alsmb.ca)

Website: [www.alsmb.ca](http://www.alsmb.ca)



### **Auction prizes include:**

Two Tickets Anywhere WestJet Flies

Churchill Adventure Package

Balloon Ride for Two

Theatre tickets—MTC - PTE- Rainbow Stage

Dining Out - Hotel Stays – Spa Packages

Original Artwork

and much more

## Walk for ALS

On November 18th and 19th, ALS Society of Manitoba Events Coordinator, Brian Campbell and several of Manitoba's rural Walk Coordinators travelled to Toronto to attend ALS Canada's annual Walk Convention and Workshop. We exchanged ideas with Walk Coordinators from all over Canada, heard about new Walk plans and goals, were updated on ALS Research news, and have returned pumped up and ready to build on the success of our 2011 Walks.



Our first Walks for 2012 are already being planned, with more to come:

**Whitemouth Walk – Friday, May 25**

**Belmont Walk – Saturday, June 2**

**Winnipeg Walk – Saturday, June 2**



## ALS/Lou Gehrig's Night

On July 4, 1939, Lou Gehrig gave his final farewell to his fans and teammates at Yankee Stadium. On June 2, 1941, baseball's "Iron Horse" succumbed to Amyotrophic Lateral Sclerosis, a disease that would come to be known as "Lou Gehrig's Disease." This summer, on Friday, June 22, the Winnipeg Goldeyes and the ALS Society of Manitoba will host ALS/Lou Gehrig's Night in memory of this great man, whose name has become synonymous with ALS. Join us at Shaw Park, as we pay tribute to this baseball hero and at the same time raise awareness and help to battle the disease that affects the lives of more than 250 Manitobans and their families. Watch as we reenact Lou Gehrig's famous farewell speech, then stay for a fun night of great Goldeyes baseball as our Winnipeg Goldeyes take on the Fargo-Moorhead RedHawks. The ALS Society of Manitoba will have an information booth set up, where you can meet ALS Manitoba staff and volunteers, as well as "Lou Gehrig" aka Dave Lemoine. Volunteers will be passing batting helmets for your generous donations.



Come out and join us for ALS/Lou Gehrig's Night at Shaw Park on Friday, June 22.

**Play Ball!!!**

## HELP US TO DRIVE OUT ALS

On Thursday, September 6<sup>th</sup>, the 9<sup>th</sup> Annual **ALS Society of Manitoba Drive for Life Golf Classic in honor of Marcel Bertrand** will be held at Bel Acres Golf & Country Club. Registration is \$200 and includes 18 holes of golf, a power cart, registration gift, buffet dinner and a bucket of warm up balls. Lunch begins at 11:30 a.m. and Texas scramble is at 12:30 p.m.



**Enter as a team or register individually. Do your part to drive out ALS.**

**These are only a few of the events we will be hosting this spring and summer. If you want to get involved in one of our events, or if you have an idea for your own event that you want to tell us about, please call Brian Campbell at the number listed below.**

**Brian – 837-1270 e-mail: [bcampbell@alsmb.ca](mailto:bcampbell@alsmb.ca)**

# HELP TO BUILD OUR GARDEN OF HOPE

## EQUIPMENT GARDEN OF HOPE FOR ALS

Money may not grow on trees, but it can help to make our Garden of HOPE grow full and healthy. Help us to fill our garden with healthy Cornflowers.

The are several ways that you can help.

**BUY A SEED - \$5.00**

**BUY A LEAF - \$10.00**

**BUY A PETAL - \$25.00**

**BUY A BLOSSOM - \$100**

**BUY A STEM - \$250**

**BUY A CORNFLOWER PLANT - \$500**

**BUY A SECTION IN THE GARDEN - \$1,000**

**HELP TO WATER THE GARDEN - \$20 OR MORE  
MONTHLY**

For every seed or part of a cornflower we can help support a client with equipment. For every Cornflower plant we can buy a new Roho cushion. Every section in the Garden of HOPE can go towards a new Track Lift System. By watering the Garden you increase HOPE in the lives of those living with ALS.

**For every donation you make a difference!!!**



Yes, I would like to purchase a \_\_\_\_\_ in the Garden of HOPE in the amount of \_\_\_\_\_

**Your donation will be helping people living with ALS.**

Enclosed is my:  Cheque  Visa  MasterCard

Card number: \_\_\_\_\_ Exp Date: \_\_\_\_\_

Name: \_\_\_\_\_

Address: \_\_\_\_\_

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

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

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

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Manitoba in motion  
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Manitoba Opera  
Manitoba Theatre Centre  
Manrex Limited  
Marble Slab Creamery  
Mariaggi's Theme Suite Hotel  
Marika Barchuk  
Marigold Restaurant  
McDonalds  
McPhillips Toyota  
Medichair  
Midwest Engineering  
Mike's Hard Lemonade  
Morden's Chocolates  
Movie Village  
Moxies Bar & Grill  
Mr. D's Tart 'N Pie  
MTS Clowns  
Natural Bakery  
Nature 1st  
Neil Keep  
New Flyer Industries  
Nick Drobot  
Ninette Motor Hotel  
Northland Healthcare Products  
Old Dutch Potato Chips  
Oma's Bake Shop  
Papa George's Restaurant  
Paper Gallery  
Parkside Ford  
PCL Constructors Canada  
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Perrier  
Perth's  
Pet Valu  
Prairie Theatre Exchange  
Procurity  
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Stewart Trophies & Engraving  
Super Lube Auto Centre  
Symmetry Massage Therapy  
Tache Pharmacy  
Tauber Music  
The Aurora Inn  
The Bake Oven  
The Craft Cupboard  
The Feast Steak & Rib House  
The Keg  
The Manitoba Museum  
The Old Spaghetti Factory  
The Original Pancake House  
The Round Table  
The Shoe Guy  
Time and Again  
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Tripwire Media Group Inc.  
True North Sports & Entertainment  
Two Rivers Gift Shop  
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ViSalus Sciences  
Wellington Estate Fine Wine & Spirits  
Western Canada Aviation Museum  
West Hawk Lake Resort  
Winnipeg Art Gallery  
Winnipeg Blue Bombers  
Winnipeg Free Press  
Winnipeg Symphony Orchestra

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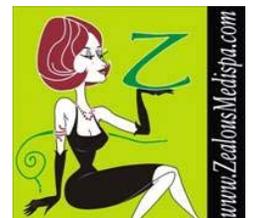


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