

Connect

THE ALS MB NEWSLETTER

FALL 2018



ALS SLA

ALS SOCIETY OF MANITOBA
LA SOCIÉTÉ MANITOBAINE DE LA SLA

MESSAGE FROM EXECUTIVE DIRECTOR



Welcome to fall – where did the summer go!!!!

In this issue you will note the enormous contributions so many of you have made, thank you to all for your commitment and support.

Knowledge is powerful, and we can all learn more about the struggles people have living with ALS/MND. Being empowered to advocate on issues that help people have a better quality of life can be a tool for healing, hope and moving forward. How can we keep this momentum going? What do we need to do? How can we better communicate between disciplines and bridge gaps, so that we have meaningful conversations?

We have the opportunity to grow our organization and think about our mission, vision and values and plan accordingly. We have a strategic plan; however, we cannot do this alone.

This is where you come in – you can help by volunteering, serving on a committee, or fundraising. Giving back to the community is a valuable experience and can help a small organization like ours meet our goals and objectives.

We often get asked, how can I give back. As mentioned, there are the tangible day to day things that can help, but you can also become a monthly donor or think about a planned gift. This can be done through designating the ALS Society of Manitoba as a beneficiary in your

will, making a bequest, or a gift of annuities, insurance and more. Speaking to a financial advisor can be very helpful. Long term planning can help you and also assist you in fulfilling your own personal wishes, as well as leaving a legacy.

The ALS Society of Manitoba supports clients and families living with ALS/MND and will always strive to advocate for quality client care, more research and to enhance quality of life. We need your help, and that is why we need to have more knowledge about the hard questions around living with ALS/MND that need to be asked and answered.

This issue of **Connect** reflects the many aspects of how you have helped us – we need your help and HOPE that you will join us and be part of the journey to make ALS/MND treatable not terminal.

DIANA RASMUSSEN
Executive Director

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ALS RESEARCH

Client Input on Radicava (edaravone)

The Canadian Agency for Drugs and Technologies in Health (CADTH) recently posted an open call for patient input on Radicava (edaravone), a drug which is under the approval and affordability pathway review by Health Canada.

In response to this CADTH's call, ALS Canada, in coordination with their provincial partners, gathered input from the ALS/MND community across the country.

Through a survey and numerous focus groups conducted in French and English, they invited Canadians affected by ALS/MND to share their experiences, perspectives and realities of living with the disease.

We want to thank our ALS/MND Community for participating in this data input; your voice has been heard.

Read the final 2018 ALS Canada CADTH Patient Input Submission: www.als.ca

Listen to what Canadian researchers say about the future of ALS/MND: https://youtu.be/4Q_ZVthPJ0s

Register for Webinar

3rd Annual Virtual Research Forum. October 17, 2018. Live presentations from Canada's world-class ALS research community, international ALS researchers and experts.

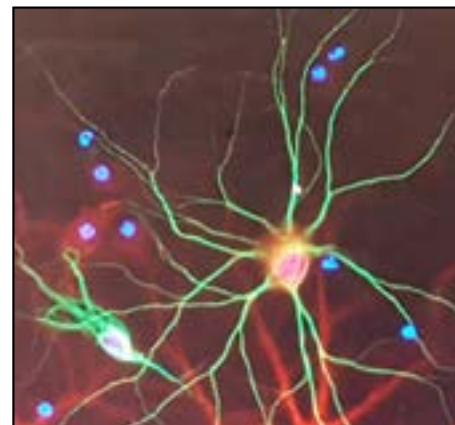
Free registration at: www.als.ca

Discoveries that may lead to effective treatments on ALS

ALS/MND research is having an unprecedented momentum. Different avenues are being developed as never before by the research community trying to better understand the disease, its evolution and its causes to find more effective treatments for the near future. To know more about where we are at, we recommend you review the periodical updates presented by the ALS Canada Research Program team, which lastly reported the following discoveries:

- NEW INSIGHTS INTO HOW MUTATIONS IN THE PROTEIN FUS LEADS TO THE DEVELOPMENT OF ALS
- A PROMISING LEAD FOR TREATMENT OF AN INHERITED FORM OF ALS
- WHAT WE CAN LEARN FROM EXTREMELY RARE ALS REVERSAL CASES
- RESEARCHERS IDENTIFY A NEW LINK BETWEEN TWO CELLULAR PROCESSES DISRUPTED IN ALS
- ADVANCES IN MODELS USED TO STUDY THE BIOLOGY OF ALS

Learn more about the current ALS Research projects: www.als.ca



PROGRAMS & SERVICES

Give a BOOST Program

In partnership with Home Instead Senior Care, this is a year-round program that collects nutritional supplement drinks. The Give a Boost Program asks people to donate six-pack Boost, Ensure and other supplement drinks to help clients to get the nutrition they need. Any time is a good time to participate and give a boost to people living with ALS/MND!

Donations of any brand of high-protein supplement drinks will be appreciated since this option is highly demanded from clients.

We need your help right now in order to sustain this program. Please help!

Drop off locations

- HOME INSTEAD WEST - 610 Sherbrook St
- HOME INSTEAD EAST - 104-250 Marion Street
- LONDON DRUGS - St. Vital Mall
- THE MEDICINE SHOPPE PHARMACY – 1A - 660 Osborne St
- ALS SOCIETY OF MANITOBA - 2A - 1717 Dublin Ave



UPCOMING EVENTS

BELMONT AND SOUTH MANITOBA WALK FOR ALS
Saturday September 8, 2018
Starting Location: Club Room, Belmont, MB
Check-In: 9:30 am
Start: 10:30 am / Distance: 5K
Support this event by participating, donating or creating your own Virtual Walk. Donations open until September 15, 2018 at: www.walkforals.ca/find-a-walk/manitoba

MANITOBANS FOR HUMANRIGHTS -TORCH OF DIGNITY RELAY
Sunday September 23, 2018
10 am - Bedson Park 460 Bedson Street
12:30 pm - 4 pm - Free Family event at The Forks. Come and cheer the ALS Society of Manitoba team! Learn more: www.mhri.ca

BUD SPUD & STEAK FOR ALS
Friday September 28, 2018.
NEW LOCATION: Canad Inns Destination Centre Polo Park – TYC Event Centre
1405 St. Matthews Avenue
*** Family friendly event
Auction of HOPE and 50/50 Draw. TICKETS \$25 – Buy your tickets now at www.alsmb.ca or call (204) 831-1510 Ext. 20

LITE UP A LIFE CAMPAIGN
December 1, 2018 to January 31, 2019
LIGHTING CEREMONY: ednesday December 12, 2018. Brummitt-Feasby ALS House 106 Kirby Drive. Learn more: www.alsmb.ca

CONTACT US:
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PHONE (204) 831-1510
TOLL FREE 1-866-718-1642
HOPE@ALSMB.CA

RECENT EVENTS

A Night of Fun, Friends & Mystery

The Cornflower Ball celebrated on April 21st was a fun and memorable night for all, with a mystery about Jessica's jewel. It was a sold-out event in a revamped themed atmosphere that raised over \$65,000 to support equipment, programs and services for our clients and families.

At the Victoria Inn Hotel and Convention Centre, our guests were delighted with a great dinner, live music, and an incredible cultural performance by enthusiastic dancers and musicians from Folklorama.

Our Rainbow and Live Auction as well as our Auction of HOPE gave out amazing prizes donated by Manitoban artists and businesses.

Thank you everybody for being a part of the new era of this signature event. Our Cornflower Ball Committee is already working on a new themed experience for next year's event. Keep tuned into ALSMB.ca and don't miss out!

SAVE THE DATE:
CORNFLOWER BALL 2019
APRIL 27TH

ALS/Lou Gehrig's Night with the Goldeyes

Do you know why ALS/MND is also known as Lou Gehrig's disease? Lou Gehrig passed away from ALS/MND in 1941.

He was the New York Yankees' first baseman playing in a then-record 2,130 consecutive games and leading The Yankees to win the World Series six times during his 17 years in the team before he was diagnosed with ALS/MND. It was on July 4, 1939 at the Yankees Stadium, when Gehrig gave the greatest speech in sports history.

To commemorate those famous words and spread awareness on ALS in our community, the Winnipeg Goldeyes and the ALS Society of Manitoba partnered to host the ALS/Lou Gehrig's Night. On May 26th, more than 30 volunteers helped with the traditional "pass the helmet" and sold tickets for the 50/50 draw in a fantastic evening with the best baseball fans ever!



June is ALS Awareness Month

Since 2015, June is ALS Awareness Month in Manitoba. This year, the Winnipeg Sign at The Forks was lit up in purple for 24 hours to bring awareness on the disease and to acknowledge and pay tribute to those living with ALS/MND in the province.

As part of the activities of ALS Awareness Month, the Winnipeg Transit Community Relations Bus was wrapped in and out with ALS/MND ads to help spread awareness on the disease around the city.



AGM / Volunteer Appreciation Evening

On June 20th, we hosted the Annual General Meeting and Volunteer Appreciation Evening at the Victoria Inn Hotel & Convention Centre.

The evening was an opportunity for the ALS Society of Manitoba to thank all our volunteers; those on our board of directors, those

that volunteer on committees and those that dedicate countless hours to making sure all our events are successful.

We also gave out the Frank Edmonds Volunteer Award and the Marcel Bertrand Award for Business Excellence to those who have made an outstanding contribution to the ALS Society of Manitoba.

To see this year's recipients of the ALS awards: www.alsmb.ca/als-manitoba/awards/



Winnipeg Walk for ALS

Every year, the Winnipeg Walk for ALS, one of the largest walks in the city, helps support people living with ALS/MND in Manitoba as well as invests in national research to make the disease treatable and not terminal.

This year's event was amazing! More than 1,800 participants gathered at Assiniboine Park to walk together, raise money, bring awareness and, more importantly, to share their HOPE for a better future for

those people and families struggling with ALS/MND.

Thank you to all walkers, donors, dignitaries and sponsors for their incredible support. So far, we have raised over \$190,000.

For those who still want to help us achieve our goal of \$255,000, online donations will remain open until September 15, 2018.

We hope to see you next year at the Walk!

SAVE THE DATE: WINNIPEG WALK FOR ALS 2019 / JUNE 15TH.



THIRD-PARTY EVENTS

A third-party fundraising event is a planned activity organized by community groups or individuals to fundraise for a cause or a non-profit organization.

For the ALS Society of Manitoba, third-party events are an important source for fundraising and a great philanthropic opportunity for people to support and give back to our ALS/MND community, no matter the format or the size.

From corporate events or programs to garage sales or lemonade stands, in-kind or money focused, these events represent an essential support for client services, programs and equipment.

If you are considering organizing an event to raise funds for the ALS Society of Manitoba, here are a few key things that might help you to make that fabulous idea come into reality:

- UNCOVER YOUR OWN MOTIVATIONS AND FIND YOUR INSPIRATION
- SET YOUR GOALS. WRITE YOUR PLAN. INCLUDE WHY, WHAT, WHEN, WHO AND HOW YOU WILL ACHIEVE THOSE OBJECTIVES
- EVALUATE YOUR RESOURCES AND ASK FOR OTHER'S HELP TO IMPLEMENT YOUR PLAN MORE EASILY
- USE YOUR PERSONAL SOCIAL MEDIA CHANNELS AND NETWORKS TO INVITE PEOPLE TO PARTICIPATE (LET EVERYBODY KNOW ABOUT IT!)
- REMEMBER TO EMPHASIZE YOUR ENTHUSIASM, GOALS AND WAYS TO HELP TO KEEP PEOPLE ENGAGED IN YOUR CAMPAIGN

We thank all those individuals and businesses who have hosted an event and fundraised for the ALS Society of Manitoba during the year!

If you are interested in hosting a fundraising activity to help the ALS Society of Manitoba, call (204) 831-1510 or check our Third-Party Event Guidelines, which will help you run your event more smoothly:

<https://alsmb.ca/third-party-events/>

THIRD-PARTY EVENTS (January to August, 2018)

- BDO JEANS DAY
- CATFISH BUY THE POUND
- CROWN UTILITIES GOLF TOURNAMENT
- GUY'S FIGHT SOCIAL
- HENRY DERKSEN MEMORIAL GOLF TOURNAMENT
- INTERNATIONAL FACILITY MANAGEMENT ASSOCIATION GOLF TOURNAMENT
- PANCAKE BEAKFAST - DUGALD, MB
- PRAIRIE DOG CENTRAL RAILWAY
- ROBERT AND DOREEN DICK MEMORIAL SKI-A-THON
- VIPOND GOLF TOURNAMENT
- WOOLY CLASSIC POKER TOURNAMENT

CONNECT TO THE ALS/MND COMMUNITY

Get to know the Board of Directors



JESSICA LORUSSO
President

Jessica was born in Northwestern Ontario in a small town called Geraldton. She believes that growing up in the north makes a person very resilient. Presently, she is a Canadian Leading Expert on Credibility and Industry Leader Development with 16 years in establishing and growing businesses to become market leaders. Jessica is one of the twelve civility master trainers in the world, a book author and an award winner.

In addition to her professional endeavours, Jessica has volunteered for three years for the ALS Society of Manitoba and has been the President of the Board of Directors since 2016. She is also an enthusiastic member of the Cornflower Ball Committee. At the Ball, she runs the registration table and loves giving a warm welcome to all the attendees.

Jessica has no personal connection to the ALS Society of Manitoba. However, she states, "this organization is a place where I belong. I am not just the president but an active member working with like-minded people".

The main reason why Jessica got involved in the Board of Directors is because she considers the ALS Society of Manitoba is a non-profit organization that does more for people suffering with ALS/MND than just fundraising. "I wanted to give my time where my activities directly affect people with ALS/MND right here in Manitoba," she adds.

To finalize, Jessica urges everybody to get involved: "Clients and their families with ALS/MND need you. We are helping people who live all over Manitoba, and the number of clients is growing. ALS/MND is not a sexy disease and it is fatal, we need to help our people NOW".



REAL PICARD
Treasurer

Real was raised in Thunder Bay, Ontario. Graduated with a degree in Business Administration, he joined the banking industry in 1980 and

worked in many locations. Real had the opportunity to work in Yellowknife, NWT, being an Auditor, as well as in various management roles. He has worked for CIBC for over 38 years and has been a Senior Business Advisor for the last 15.

Real's connection with the ALS Society of Manitoba was a coincidence between a family story and his work. "As my mother passed away in 2004 with a combined diagnosis of Dementia and ALS, I have always wanted to be able to participate in some way. It was through my role with the bank that I connected with the ALS Society of Manitoba".

He became a board member in June of 2016, wanting to assist the Society in the finance area. Shortly after joining, he became Treasurer. "Within the first year, I realized how much more I could become involved within the Board. It is not only gratifying in knowing you are helping in some way for a good cause, but also knowing what a great job the ALS Society of Manitoba is doing to provide support and service to people afflicted with this illness", Real explains.

According to Real Picard there are many challenges and opportunities the Society faces, "I look forward to my continued involvement as a Board Member and I would encourage others to volunteer in the many activities the Society has. Everyone has a skill or talent that can be shared to assist someone else, as an individual or in a group. Volunteering is a great way to discover who you are and how you can assist your community".

WOULD YOU LIKE TO BECOME A BOARD MEMBER? (204) 831 1510 EXT. 20 /HOPE@ALSMB.CA



MICHELINE CHAPUT
Vice President

Micheline was born in St. Pierre-Jolys, a small town in southern Manitoba, but moved to Winnipeg in her late teens to go to university. She worked and truly enjoyed working as elementary school teacher for 15 years and as school counsellor for another 15 years of her career. Now retired, she loves the company of her children and grand-children and enjoys gardening, golfing and bowling.

"While at my last school before retirement, I had the wonderful experience of working with a principal who cared deeply about his students. He fostered a learning environment where the students were expected to learn to their fullest and be good, kind citizens. Unfortunately, his career was cut short when he was diagnosed with ALS/MND," she explains.

In 2011, having retired and looking for a way to give back to the community, Micheline noticed a call for volunteers on our Board of Directors and realized that this would be a good opportunity to honour her wonderful principal and to help a good cause.

As a member of the Board of Directors, she attends monthly

meetings, supports the various fundraising activities and promotes our cause any way she can. She is also a member of the Federation Council of ALS Societies across Canada and part of the Advocacy Committee.

Micheline encourages anyone looking to add a new dimension to their life, to help educate the population about ALS and motor neuron diseases and to give meaningful support to the people living with ALS/MND. Please join the ALS Society of Manitoba. "Being involved with the ALS Society of Manitoba allows me to support a great cause. I have met a number of interesting and dedicated people all working toward the same goal. It has given me new insight into this disease, educated me on all the research that is being made to combat ALS/MND and has given me hope that a cure will be found," she highlights.



BELINDA WIEBE FRIESEN
Board Member

Belinda was born and raised in a small village southeast of Altona, Manitoba. Since 2007, she has worked for Sorenson Communications as a Video Relay Service Interpreter (VRS), providing communication services to deaf communities

across the United States. Family has always been and, still is, very important to Belinda. "I come from a family of nine, and when my mom, Dora, was diagnosed with ALS, we came together as a family and, as a family; we surrounded her with love and support as we walked together on the path that led to her passing in 2013," she expresses.

With her mom's diagnosis, she gained an insight as what she calls the "challenges and barriers" that face people living with ALS. She explains "this experience made me realize the importance of the ALS Society of Manitoba's support services and the need for medical staff and caregivers to be educated on the proper treatment and care for individuals living with this disease. With that said, before my mom passed away, I promised her that I would find a way to share our story, advocate for those living with ALS and continue to have hope for a cure".

In 2016, Belinda joined the ALS Society of Manitoba's Board of Directors and, as a board member, she has participated in events such as Lite Up a Life Campaign, Walk for ALS, Cornflower Ball, Ice Bucket Challenge, and the Bud Spud & Steak for ALS. These events have given her the opportunity to make community connections with families living with ALS and share stories of struggles, joy and tears.

"The Society relies on these fundraising events to provide services and, with the help of volunteers and participants, they are able to do so. Therefore, I encourage you to join us. Together we can make a difference and together we can find a cure," Belinda emphasizes.

Connect

SPONSORS & SUPPORTERS OF THE ALS SOCIETY OF MANITOBA



Red River



RELIABLE MOBILITY



- | | | | | |
|---|----------------------------------|-------------------------------|------------------------------------|--|
| 3M Canada | Credit Union Central of Manitoba | Joey Restaurants | Oliv Tasting Room | Stride Ahead Sports |
| Air Unlimited | Crystal Clear Water | Johnson Family | Olive Garden | Super Value Home Services |
| Alan Lacovetsky | D Jay's Ichabod's Lounge & Patio | Johnston Group | Oma's Bake Shop | Swiss Chalet |
| Alfies | Dan & Eileen Coates | Keurig | Pamela Brown | The Bake Oven |
| Arctic Ice | Davids Tea | Kite and Kaboodle | Panago Pizza – Main St | The Keg Steakhouse & Bar |
| Assiniboia Downs | De Luca Fine Wines | Koch Stainless Products | Pancake House | The Wine House |
| Betula Lake | Denny's Restaurant | Lakeview Hotels & Resorts | Papa Murphy's | Thunder Rapids |
| Booster Juice | Domino's Pizza | Landmark Cinemas 8 Grant Park | Pary Grewal | Tinkertown |
| Bornhorst Mechanical Inc. | Edward Carriere | LightVisions | Peppercorn Restaurant | TJX Canada |
| Boston Pizza - Lionel | European Skin Care Plus | Lilac Resort | Perth's | Tom Carlyle |
| Brandyourland.ca | Flo Essence | Lisa Scrivens | Perogy Planet | True North Sports & Entertainment |
| Browns Socialhouse | Folklorama | Manitoba Museum | Prairie Dog Central Railway | United Association Local Union 254 |
| Calabria Market & Fine Wines | Fort Garry Hotel | Manitoba Nurses Union | Rae and Jerry's Steakhouse | United Rental |
| Cambrian Credit Union | Fukumoto Fitness | Manitoba Opera | Rainbow Stage | VIA Rail Canada |
| Canadian Beverage Container Recycling Association | Fun Shots Photo Booth | Marigolds Restaurant -Inkster | Red Lobster Restaurant | Victoria Inn Hotel & Convention Centre |
| Canadian Brewhouse | Generation Green | Mark Sobrevinas | Rocco's Pizzeria | VIP Home Care |
| Carlson Truck Outfitters | Genevie Henderson | Mastermind Toys | Rubber Ducky Resort and Campground | Water Mart |
| Celebrations Dinner Theatre | George Chapman | McNally Robinson | Rumor's Restaurant & Comedy Club | Western Marble & Tile Ltd. |
| Chatters | Grace & Company | Midland Appliance World | Salisbury House | WestJet |
| Children's Museum | GRS Financial Services Inc. | Milkman Distributors | Saucers Café | Wilf's Elie Ford Sales Ltd. |
| Clear Spring Ice | Gunn's Bakery | Mona Lisa Ristorante Italiano | Save on Foods | Winnipeg Blue Bombers |
| Confusion Corner Bar & Grill | Harper Media | Mongo's | Shapers | Winnipeg Goldeyes |
| Cookies by George | Hilary Druzman | Moxie's Bar and Grill | Shooters Golf Course | WOW! Hospitality Concepts |
| Coras | Holiday Inn (Airport West) | Nygaard Fashion Park | Silver Heights Restaurant | WPS/ Community Relations Cadets |
| Cottage Bakery | Ichiban Japanese Steakhouse | Oakley Optical | | WPS/ Community Relations Division 51 |
| | JellyFish Float Spa | Old Dutch | | Zealous Medi SPA |