



The ALS Society of Alberta

Prairie to Peak



Ice Bucket Challenge

The Ice Bucket Challenge has raised international awareness, along with significant donations to the ALS Community. The ALS Society of Alberta is so grateful to everyone who participated and donated!

“The unprecedented awareness has changed the landscape of the ALS cause and more importantly, provides hope and care for people living with and affected by ALS,” said Karen Caughey, executive director of the ALS Society of Alberta.

Read more about the Ice Bucket Challenge on Page 10.

Client Services and Equipment Support Expansion in Edmonton



We are very excited to announce that the Edmonton Office is now located at 5418 97 Street NW, in Edmonton. Our new office now includes a warehouse that stores equipment for our Equipment Loan Program. Having this new combined office/equipment storage space assists the ALS Society in expanding services in Edmonton and Northern Alberta, to better serve our clients and their families. The space also allows easier access and control of our equipment, as well as improves the process for individuals to receive equipment in a timely manner.

The Edmonton Office has also expanded to increase our support to families. In February, the Society welcomed Robert Rudd, as a part-time Equipment Maintenance Assistant. This is a new position that greatly enhances the scope of the Equipment Loan Program for the North Region.

We said goodbye to Peggy Ziebarth who moved to British Columbia to retire. While Peggy was only with us for a few short months, we will greatly miss her! We would like to formally welcome Brenda MacGregor as the new part-time Office/Volunteer support in the Edmonton Office.

At the end of April, Skylin Herba, Client Services Coordinator returned to school to work on her Masters in Social Work. Skylin, thank you so much for all of your hard work - we will miss you dearly, as will the families you have worked with. Christy Reschke, who has been with us since last summer through the Grant McEwan Social Work program, will be continuing as a Client Services Coordinator. We will be hosting an open house on Tuesday, September 9th to show off our new office!

ALS Society Updates

Changes to our Communication by Mail

As with many organizations feeling the pinch of mounting printing and mailing costs, and minimizing our impact on the environment, we will now be emailing out our newsletter. We would like to email invitations and information regarding our events, research forums, announcements and updates. Therefore, December's newsletter will be our last printed and mailed version. All future newsletters will be emailed.

We are also working on the process to email donation tax receipts where possible. If this format will not work for you, please contact our office at (403) 228-3857.

Anti-spam Legislation

Canada's anti-spam legislation came into force on July 1, 2014, and requires that we obtain your consent to send you electronic communications. An email was sent out at the end of June requesting your permission. If you did not receive an email and would like to be added to our email list, please contact Diane@alsab.ca

We hope you have found our communications regarding our events, research forums, announcements and updates informative and we thank you for your ongoing interest.

Online - "Heartbleed Virus"

Recently, the Canadian community was made aware of a computer virus that has the potential to put a significant number of the Internet's websites at risk. Dubbed "Heartbleed", this bug allows information to be accessed that would normally be protected by some versions of OpenSSL.

We can confirm that our donation system, Artez Interactive was not vulnerable to the Heartbleed Virus, and your secure contact and payment information was not affected.

Travel Tips for people living with ALS By Roger Brightwell

I was asked to pass on tips and tricks I have learnt along the way for a person traveling with a disability. With some thought, ingenuity and perseverance, we have managed some great trips with me in a power wheelchair and using a bi-Pap 24/7. To give you an idea of travel that is possible, we have done a trip to Ottawa and five trips to Eastern Europe. I hope I can ease tension and inspire others to enjoy traveling as well.

Airplanes can present some challenges but with patience and a little ingenuity the challenges can be dealt with. After a few trips, I have learnt a few tricks to deal with these issues. The issues I am referring to are: dealing with airline staff, what is needed for the flight, areas of concern with traveling with a wheelchair, traveling with an attendant.

The first thing to prepare for is dealing with airline staff. Depending on your needs, they may not know how to deal with your requirements for travel. If you need assistance to get on and off the plane, you may have to speak to a supervisor. As well, if it is getting difficult dealing with someone you may again have to ask to speak with a supervisor. A point to keep in mind is that the airlines are a service provider and they charge you for their service. If you are not getting the service you require, do not be afraid to ask to speak to a person that is capable or has clearance to provide to you with the assistance you need.

When booking your flight (online or with a travel agent) check all boxes that are applicable. It is likely that you will have to contact the medical desk. When you reach them, make sure to take the person's name. There may be additional phone calls, so it is easier to deal with the same person. It is wise to keep a list of all your requirements (if you need bi-Pap/ventilator, oxygen, tube feeding supplies, assistance required, traveling with an attendant etc.) to refer to at any time.





Travel Tips Cont'd By Roger Brightwell

Continued from Page 2

When booking your flight keep in mind that most airlines have free or reduced fares for an attendant supplying assistance. The normal rate for attendants are free within Canada, and 50% in North America. Overseas flights are usually full fare. Other privileges of traveling for the attendant, is choice seating. Airlines will usually bump other passengers so the attendant will be next to the person with a disability.

Depending on your level of disability, a medical clearance (fit to fly) letter may be required. The letter can be downloaded from the airline's website. This letter will need to be filled out by your doctor usually within 2 weeks of travel date. Once it is filled out, it will have to be forwarded to the medical desk. I found it best to call to verify every step of this procedure (ie. confirm received letter, confirm clearance, etc.) This will aide in making sure all details are looked after. On the day of travel, I would suggest to arrive at the airport about an hour (or more) sooner than the suggested time. It takes a little longer to check in and get through security. It is better to come earlier than be rushed.

If traveling with a power wheelchair, extra preparation is needed. There will be forms on the airline's website for power wheelchairs. These forms will require dimensions, weight, etc. The medical desk will be asking for this when you call. The reason for this is to make sure your chair will fit through the cargo door. There are a few other things to keep in mind when traveling with a chair.

Wheelchairs have a tendency to get damaged when being handled by airline staff, so here are some things to watch out for. Wheelchairs need the batteries

disconnected before loading them on the plane. It is best that someone in your traveling group knows how to disconnect and connect the batteries on your chair. The cargo person may not know how to disconnect the batteries. Even worse the person at your destination may not know how to hook them back up. This can be a big problem if no one knows how to connect everything together.

Pieces being broken are another area of concern. The more accessories your chair has, the more care that is needed. The cargo handlers will try to lift your chair by whatever they can grab hold of. The problem is, most accessories will break if your chair is lifted by them. What we have learnt is to take off all removable accessories. I am referring to: headrest, adjustable legs, control pads, cushion, etc. Make sure to wrap the pieces in bubble wrap and put the pieces in a carry-on bag.

To take extra precaution to label the pieces that may break (arm rests, seat platform, etc) Orange duct tape and a Sharpie pen work well. Adding lifting loops to the tether points help as it gives the cargo handler an easy point to lift the chair that will not cause damage. Also with your Sharpie, label the tether straps "LIFT HERE". The brakes should be well indicated and/or labeled as well. This may seem like over kill but looking at it from the cargo handlers view, they have a very short time to unload the plane. Prepare your chair to be in the most structurally sound state and labeled so it is identified where and where not to lift, and brakes on and off positions, it makes their job easier and your equipment is more likely to survive the trip.

If your trip has a connecting flight, ask for your chair to be checked through to your destination. If you do this they will usually put your chair in a container and it will be handled less. So less chance of damage to your chair.

It may be wise to find the contact information of wheelchair dealers at your destina-

tion. If your chair needs to be repaired, it may help to have this information to give to the airline to repair the chair.

The next step in the procedure is getting on the plane. Transferring from your wheelchair to the plane can be done relatively smoothly. The airline will transfer you to a small chair called a Manchester Chair. It will fit up the aisle of the plane and they will transfer you to your seat on the plane. To make it easier on me and airline staff, I use a transfer sling. This gives the airline staff a place to lift from, and is considerably easier on me. Last November on the flight to Ottawa (WestJet airlines) they had a lift called the Eagle, they put me in a sling and lifted me out of my wheelchair, then transferred me to my seat. I found this more comfortable than the Manchester chair. They will transfer you just outside of the airplane door. It is best to suggest to the staff at the gate to transfer you to the Manchester chair early. A few extra minutes makes it a lot less stressful. People requiring assistance are the first to get on the plane. It is better to get on the plane as soon as possible. Soon after you are on the plane, general boarding starts. If you are not settled in when people start to board, it will be difficult.

At your destination everything should happen in reverse.

Traveling can be enjoyable with the knowledge of what to expect and preparation for it. The airlines are set up for people traveling with disabilities. With planning ahead of time, both you and the airline can prepare for your trip. There is a solution to every obstacle. It just takes some ingenuity and perseverance and you can have an enjoyable trip.

Sadly, Roger Brightwell passed away on June 4. We are so grateful for all of the stories that he shared, and our hearts are with his loved ones during this difficult time.

Do you have any tips or tricks to share with the ALS Society that would help others living with ALS?
Email them to
Lindsay@alsab.ca

Third Party Events & COMMUNITY FUNDRAISERS

Disabled and Dangerous Online Launch

On December 19, 2013 producers of the short film, Disabled and Dangerous launched their film on YouTube. It was a hit at the original release during the Calgary Film Festival in June 2012 and after entering it in numerous film festivals, the producers were ready to officially launch it online. The film was born from an idea of Barry Varga and other friends living with ALS. Producers Kyle and Levi McCachen of Stokes Media worked for months to bring the film to life. The online launch triggered media interviews across the province as well as generous donations and awareness. The group has recently won the ALS Canada 'Tony Proudfoot Exceptional Public Awareness Program Award' for their work.

Darby Chrest

The Annual Darby Chrest Memorial Bowling Event was once again held at Heritage Lanes in Red Deer by Shelby Chrest. On January 1, 2014, \$5,220 was raised through this year's event. Thank you to Shelby for organizing it once again!

Comedy for a Cause

Rick Bronson's The Comic Strip in Edmonton hosted the first annual Comedy for a Cause event featuring comedian Ralph Harris. Through ticket sales, raffle sales and donations, over \$2,400 was raised! Thank you so much!

Infiniti South Edmonton

A special thank you to Jonathon Sadiq, Service Manager for Infiniti South Edmonton, a division of Go Auto, who donated \$500 through Go Auto Random Acts of Kindness for all employees for the month of February.



Edmonton WALK for ALS Kick-off Luncheon

The Annual Edmonton WALK for ALS Kick-off Luncheon was held on Thursday March 6, 2014 at the Chateau Nova Yellowhead. Over 30 people attended the luncheon where we had a variety of speakers including: Dave Williams, Board Member; Darlene Brady on behalf of her father Mack Skoreyko who is this year's Ambassador; Taylor Boulton, Team Captain for Rob's Riot; and more. Thank you to Canadian Western Bank for sponsoring the lunch.

First Annual Edmonton WALK for ALS Pub Party

On Saturday March 8, the Edmonton WALK for ALS committee hosted their first annual Pub Party at Hudson's Campus. The event featured the ALS color purple themed photo booth, door prizes, a prize raffle as well as purple beer! Thank you so much to Lukasz Herba Images for photographing the event and taking the fun photos at the booth. Over \$1,700 was raised at the event through ticket sales and the raffle.



Calgary International Auto and Truck Show

The ALS Society of Alberta had an amazing opportunity to partner with the Calgary Motor Dealers Association and provide volunteers to take entry tickets at the March 11-16 Calgary International Auto and Truck Show. In return, the CMDA made a very generous donation. We are so thankful to this group for allowing us to continue being part of their fundraisers and events. Special thanks to Jim Gillespie and the Executive Board!



Order of the Eastern Star - Chinook Chapter #133

Thank you so much to Lee Clay and the members of the Order of the Eastern Star - Chinook Chapter #133 for a donation of \$13,000 to the ALS Society. We really appreciate the support towards our programs and services in Alberta.

Telus

As a response to a story Christy sent out to colleagues about her dad who is living with ALS, fellow Telus Employees on the 7th floor Telus Plaza South rallied and donated \$590 to the ALS Society. Thank you so much for your generous gift!



Red Dress Run

The Red Dress Run took place on May 10. It is the Edmonton Hash House Harriers biggest annual event with over 200 runners. Male and female runners alike, don red dresses and run (and party) on the premise of supporting a charity. This year, the event supported the ALS Society of Alberta. Thank you to Richard Nally, as well as all supporters and participants!



Cooperators Insurance

A cheque for \$15,000 was presented to the ALS Society by the Cooperators Insurance Volunteers in Action Committee. Thank you to David Christensen who led the group on their fundraisers this year.

Wheelchair-For-A-Day

Coalhurst High School students set out to raise \$700 in the ALS Wheelchair-for-a-day Awareness Project. These talented fundraisers managed to double their goal, and raised \$1,466.83 for the Society! Great work Michael Saad and students!

Second Annual ALS Pub Party

The second annual ALS Pub Party took place on June 7 at Bo's Bar & Grill in Red Deer. This event included live music from the Preying Saints, raffles, door prizes and an appetizer buffet! Thank you to Houaida Haddad for coordinating this event!

Annual Precision Charity BBQ

The Annual Precision Charity BBQ took place on June 20 at Precision Well Servicing in Red Deer! Activities included a silent auction, dunk tank, raffles, bake sale, sumo suits, sparkle tattoo artists, games and more! Thank you to Don Pack, Katelyn Burrows and the committee for coordinating the event, and to everyone who participated!



Swing for ALS Golf Tournament

The Swing for ALS Golf Tournament was hosted in Cold Lake on July 5 at the Grand Centre Golf & Country Club! This event raised over \$10,000, making it a huge success! Thank you to all participants, volunteers and sponsors!

STOMP out ALS

Jessie Lipscombe and Lisa Robitaille organized a flash mob in Edmonton on July 12 at Cherry on Whyte Ave. to raise awareness about ALS! This eye-catching event was featured on Breakfast Television in Edmonton! Thank you to all participants!

Quonset Days "The Greatest Outdoor Party on Dirt"

Seven hundred people showed up for Quonset Days from July 18-19! The annual fundraiser takes place just outside of Seven Persons, and began as a tribute to Peter Biemans who passed away in 2009 from ALS. This year's event included performances by: Phoenix, Men Without Shame, Jay Bowcott, Julian Austin and Aaron Pritchett, as well as a Battle of the Bands competition. It was an amazing weekend to gather and celebrate the lives of those affected by ALS! Thank you to the Biemans Family, and to everyone who participated!



Stanley Carlstad Ball Tournament

Eleven teams participated in the fifth annual Stanley Carlstad Memorial Ball Tournament in Bear Canyon from July 19-20! The event included a silent and live auction, as well as a craft sale hosted by Camryn Ollenberger, Emma Carlstad and Brenna Carlstad! This event has raised \$12,049 for the ALS Society of Alberta. A BIG thank you to all participants, and to Trudy Roy for all of your hard work in coordinating this event!

ALS Sucks Wind Calgary Banff Ride

The 2014 300K ALS Sucks Wind, for both ALS Canada and ALS Alberta, Calgary Banff Ride raised \$21,385!! A BIG thank you to Jim Robinson, and to all participants and supporters!

Sax's Soldiers Golf Tournament Beaumont

Sax's Soldiers Golf Tournament took place at the Colonial Golf Club in Beaumont on August 15. A big thank you to all participants and supporters.



Upcoming

Year of the Beard

January 3, 2015

Wildcat Clubhouse, Rundle Park

For more information, contact

Meghann at

meghann.i.tanner@gmail.com

The WALK for ALS

The WALK for ALS is an annual event that aims to raise awareness about the disease, while collecting donations to aid in ALS research and client support services. This year, the ALS Society of Alberta and volunteers planned 11 WALKS for ALS in different locations across the province. We still have one upcoming WALK in Lethbridge on Sept. 20! The WALK for ALS is made possible by the hard-working walk coordinators and volunteers in each town, and by all of our participants and sponsors!



Barrhead

Barrhead

On May 24, the town of Barrhead hosted their first annual WALK for ALS! The event's fundraising total was over \$12,500! The WALK was hosted in partnership with the town of Barrhead Fun Run, and was followed by a BBQ lunch and refreshments. Thank you to all participants, sponsors, and to Jody Round for coordinating the WALK!

Camrose

Camrose hosted a WALK for ALS on June 28, followed by a BBQ in Mirror Lake Park. They managed to raise over \$65,500, making the event a huge success! Thank you to everyone who participated, and to all of our fabulous sponsors! Another warm thank you goes out to Dianne Friesen, who selflessly coordinated this year's WALK!

Cold Lake

Michelle and Pat Feduniak worked hard to coordinate the annual Cold Lake WALK for ALS at the Lakeland Lutheran Church on Millennium Trail on June 7! This year's event raised over \$17,400. Thank you to all participants and sponsors!

DeBolt

The DeBolt WALK for ALS was hosted on August 16 at the DeBolt Centre. This event raised over \$19,000! Thank you to all participants and sponsors, as well as Wendy Holscher for coordinating the WALK!

Edmonton

Edmonton hosted their 14th annual WALK for ALS on June 7. This event was a huge success, bringing in over \$246,000 for ALS research and support services! The WALK was hosted in William Hawrelak Park, and was followed by a BBQ. Thank you to Lindsay Rodriguez and the Edmonton WALK committee for all of your hard work, and to all participants and sponsors!

Hinton

Hinton hosted their fourth annual WALK for ALS at Maxwell Lake on June 15. They raised over \$12,100 making this year's event the most successful one yet! Thank you to all participants and sponsors, as well as Beth MacCallum and Tim Scaife for coordinating the WALK.



Edmonton

Peace District

On June 1, the 2014 Peace District WALK for ALS took place in the Normand Boucher Community Arboretum! This year's event raised over \$1,200! Thank you to Johanna Downing for coordinating this year's walk, as well as to all participants and sponsors!

Spruce Grove

The Spruce Grove WALK for ALS took place in Central Park on June 7, and raised over \$13,200! This year's event was followed by a BBQ and prize giveaway. Thank you to Yvonne Cadwell and the committee for coordinating this year's WALK, as well as to all participants and sponsors!

Red Deer

Red Deer hosted the WALK for ALS in Great Chief Park on June 21. This year's event raised over \$115,100. Thank you to Michelle Parker, Brenda Clampitt and committee for coordinating this year's WALK! We are very grateful to have such amazing volunteers, participants and sponsors!

Vegreville

Thank you to everyone who participated in the Vegreville WALK for ALS on August 23! Over \$8,100 was raised! Thank you to Dina Bottrell for coordinating the WALK!

The 18th annual Betty's Run for ALS

On June 8, over 1,700 people gathered in Calgary for the 18th annual Betty's Run for ALS! This event began in honour of Betty Norman, who sadly passed away from ALS in 1997. Betty was the driving force behind the 1997 "This One's for Betty" walk and run. Betty's courage and determination is celebrated each year at Betty's Run for ALS, which continues to inspire care, hope and community. We would like to thank everyone who helped make this year's event a huge success! Together we raised over \$550,000, bringing Betty's Run to the \$6 million fundraising milestone.



We would like to thank our Honourary Chair, Jim Gray, and Mayor Nenshi for their attendance and speeches at the event. We are also very grateful for our 2014 Betty's Run Ambassador, Ineke Smit, a former nurse who began her battle with ALS in 2012. To learn more about Ineke, visit www.alsab.ca/events/bettys-run-for-als/ambassador. A big thank you goes out to the Betty's Run organizing committee. We couldn't have done it without you!

Upcoming WALKS for ALS

Lethbridge (September 20, 2014)
Registration: 9:30 AM; Start: 11:00 AM
Stay after for a BBQ
Henderson Lake
Horseshoe Pit Group Picnic Area
Email: lethbridgewalk@alsab.ca



CTV's Inspiring Albertan

We are very excited to announce that Client Services Coordinator, Jane Rivest was June 25th's Inspiring Albertan! Jane was featured on CTV news for all of the hard work that she has done for Betty's Run for ALS, and for her clients everyday. Her interview can be seen online at www.calgary.ctvnews.ca/more/inspired



The 12th annual ALS Charitee Golf Tournament

On June 16, the 12th annual ALS Charitee Golf Tournament was held at Pinebrook Golf & Country Club. This event included a Texas scramble, BBQ lunch, silent and live auction, wine raffle, as well as a steak dinner for all teams and volunteers. This year's tournament raised over \$104,000! Thank you to all donors, sponsors and participants, and to the ALS Charitee Golf committee! We couldn't have done it without each and every one of you!





The ALS Society of Alberta

"The Amyotrophic Lateral Sclerosis Society of Alberta is dedicated to making each day the best possible day for people living with and affected by ALS by providing support, facilitating the provision of care, promoting awareness, helping find a cure and advocating for change."

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Ice Bucket Challenge



The #IceBucketChallenge has taken the world by storm in the last couple of weeks and has made an amazing impact on the ALS community in Alberta and across Canada! Over \$200,000 has been donated to the ALS Society of Alberta, and nationally, over \$12 million has been raised. Funds donated to societies in Canada will support both national ALS research, as well as people living with ALS. It is amazing to see so many people posting videos in honour of loved ones to help raise awareness and funds for ALS. We cannot thank everyone enough for the outstanding support we received during this initiative.

What is the #IceBucketChallenge?

Participants of the challenge are nominated to dump ice water onto their heads, film it, post it online, and then nominate someone else to raise awareness about ALS. If desired, you may also make a donation to the ALS Society of your choice. If you don't do the challenge, you are asked to donate also! Make sure to tag your video with #ALSAB and #IceBucketChallenge.

Donation Form

I would like to join the ALS Society of Alberta's Monthly Giving Program

I authorize the ALS Society of Alberta to withdraw my monthly donation of \$_____ from my bank account at the beginning / middle (circle) of each month. (Please attach a blank cheque marked VOID)

I authorize the ALS Society of Alberta to charge my monthly donation of \$_____ to my credit card at the beginning / middle (circle) of each month. (Fill out credit card information below)

Date _____ Authorizing Signature _____

I am enclosing a one-time donation of (circle) \$25 \$50 \$100 \$250 Other \$_____

____ Enclosed is a cheque payable to the ALS Society of Alberta

____ Please charge the above amount to my credit card (Fill out credit card information below)

Please send my charitable tax receipt to:

Surname _____ First Name _____

Address _____

City/Town _____ Province _____ Postal Code _____

Phone _____ Email _____

Credit Card Information

Select: Visa MasterCard American Express
Credit Card Number _____ Expiry Date _____

Please return form to the ALS Society of Alberta Provincial Office.

Your gift will help us to make each day the best possible day for those living with and affected by ALS.

PRIVACY STATEMENT: YOUR PERSONAL INFORMATION WILL NOT BE TRADED, SOLD OR SHARED WITHOUT YOUR KNOWLEDGE OR CONSENT. FOR MORE INFORMATION, PLEASE CALL THE ALS SOCIETY OF ALBERTA'S PROVINCIAL OFFICE.

Charitable Tax Receipts will automatically be issued for donations of \$25 or more.