



The ALS Society of Alberta

Prairie to Peak



A BUCKET FULL OF THANKS!

The summer of 2014 will forever be remembered as the “Ice Bucket Challenge” across the world and in the ALS Community. \$16.2 million dollars were raised in Canada because of the generosity of more than 260,000 Canadians. ALS Societies have invested \$10 million in ALS research and \$6 million in programs and services that deliver critical support to Canadians living with ALS. The ALS Societies are also proud to announce that the funds for ALS research will be matched on a 1:1 basis through a new research partnership with Brain Canada, bringing the total investment in ALS research to \$20 million. Over \$2.8 million was raised by Albertans, with a generous contribution going to research, and the remaining portion staying in Alberta to support and enhance the services provided by the ALS Society of Alberta. Services include: mobility and communication equipment provided at no cost, home support visits, coordination of care in the community, support groups across the province, assistance for children through our Support for Champions program, and advocacy for the best possible support for people living with ALS.

“We cannot underestimate the awareness that the Ice Bucket Challenge raised about ALS and its impact on all those affected by it. While the funds raised are incredibly appreciated, the Ice Bucket legacy will be a heightened understanding of what this disease is, what it means to those living with it and why we focus our energies on support, treatment and research.” - **Tara Pentney, ALS Alberta Chair**



Exciting Announcement!

We are thrilled to announce that Mikael Backlund from the Calgary Flames has chosen the ALS Society of Alberta as one of his charities of choice. Mikael has shown immense dedication and support across Calgary, and we are so proud to be working with him. He actively supports a number of different causes, making him an excellent role model for the Calgary community. Mikael and his girlfriend, Frida are passionate about supporting the ALS cause. Having been touched by ALS, Mikael and Frida have quickly become a strong part of the ALS Community.

Mikael will promote the ALS cause while personally donating \$200 for each point he earns over the season. The ALS Society is thrilled to have such an amazing leader supporting and promoting ALS. Mikael and Frida truly represent what community is all about.

Check out the newsletter insert for pictures from the Ice Bucket Challenge in Alberta!

Board Update

On October 4th, the staff and board members got together to learn, plan and express our mutual gratitude for all who so generously contributed their time, energy, connections and warmth to raise funds and awareness through the Ice Bucket Challenge. The day started with a presentation from Dr. Doug Cave who provided us with some useful tools and insights that will help us maintain strength and compassion in our work and daily lives. We spent some time getting to know each other a bit better, with all the board members sharing their background and motivation for being a part of this great organization.

In the afternoon, we looked at the pillars of our strategic plan, and identified ways in which we can enhance them. Advocacy, governance, research and fulfilling our mission of making each day the best possible day were the main areas of focus for our day.

At the end of the day, we asked everyone for a summary of their experience of the day. Words like: new friendships; resilience; fabulous; hope; open to new possibilities; impactful; optimism and an overwhelming sense of gratitude were just some of the thoughts and feelings that emerged as people left to continue to serve the people who connect with the Society.

ALS Canada Awards

The Varga and McCachen family recieved the Tony Proudfoot Exceptional Public Awareness Award for their commitment to Disabled and Dangerous, a fabulous film meant to raise awareness and funds for ALS. Congratulations!



This is our last printed newsletter. Starting with the next issue, all newsletters will be distributed electronically. If this will not work for you, please email diane@alsab.ca.

Research Update

We are proud to announce funding for a new clinical trial from your donations through the ALS Ice Bucket Challenge and ALS Canada's partnership with Brain Canada and the Government of Canada

The Arthur J. Hudson Translational Team Grant was first announced on May 3, 2014 at the ALS Canada Research Forum and the inaugural competition deadline was July 1, 2014. This new grant program is designed to fund teams of Canadian researchers to accelerate the movement of ideas out of the laboratory and into the clinic with the hope of assisting development of new therapeutics for ALS. It is the cornerstone of our ALS Canada Research Program designed to emphasize bench-to-bedside translation. For the first time ever, ALS Canada, in partnership with Brain Canada, have utilized an International Peer Review Panel consisting of seven European and American ALS experts, spanning the basic to clinical spectrum, who convened in Toronto in November to determine the top project amongst strong competition.

It is a great pleasure to announce that the recipient of the first Arthur J. Hudson Translational Team Grant is a team led by Dr. Lawrence Korngut, MD at the University of Calgary and also includes Dr. Lorne Zinman, MD from Sunnybrook Health Sciences Centre and University of Toronto. Together, they will pursue "A randomized controlled trial of pimozide in subjects with ALS"; a Phase II study involving 100 participants across 8 ALS clinics across Canada.

This trial, led by the Principal Investigator of the Canadian Neuromuscular Disease Registry (CNDR) and the Chair of the Canadian ALS Research Network (CALS) will examine whether pimozide, a drug already approved by Health Canada for use in psychoses like schizophrenia and Tourette's syndrome, might slow progression of ALS. Pimozide is particularly effective at stabilizing neuromuscular function, which means it can strengthen the connection where the motor neuron meets the muscle (called the neuromuscular junction or NMJ). It is hoped that by strengthening this connection, there will be preservation of transmission of signals from the brain to the muscle and slowing of paralysis in ALS. (continues...)

Please visit alsab.ca to view the full article

2014 ALS Canada – Brain Canada Discovery Grant recipients

Dr. Heather Durham (Montreal Neurological Institute) – Epigenetic mechanisms underlying dendritic atrophy in ALS

Dr. Charles Krieger (Simon Fraser University) – Use of bone marrow cells to deliver single chain antibodies in ALS

Dr. Alex Parker (Université de Montréal) – Investigation of the innate immune system and motor neuron degeneration in genetic models of ALS

Dr. Janice Robertson (University of Toronto) - Characterizing the C9ORF72 protein interactome for identifying novel pathogenic pathways in ALS

Dr. Melanie Woodin (University of Toronto) – Synaptic inhibition in the motor cortex of an ALS mouse model

Support for Champions

In 2004, the Support for Champions program was created in New Brunswick by Gilles LeBlanc. Gilles was beginning his own journey with ALS and declared that his foremost wish was that his two young children would “enjoy a non-interrupted journey through childhood” despite his illness. The ALS Society of Alberta adopted the Support for Champions program in order to promote and support children who have been affected by ALS. The program provides financial support to children and their families to allow them to participate in normal childhood activities. Common programs that children apply for include: music, art, drama lessons, sports activities, camps, assistance with school fees/trips, or to participate in counselling sessions.

SASYNIUK FAMILY

“The Support for Champions program has helped Alex continue her love of dance. This is her seventh year of dance and she is currently in RAD Grade 3 Exam and Jazz Grade 3. Currently, she dances four times a week. She also participated in the Alberta Nutcracker Ballet in December 2013 and was accepted again for the 2014 performance.”



“The Support for Champions program has helped McKenna continue her training in TaeKwon-do. She is in her 3rd year and is currently a yellow belt working on her green stripe. She trains three times a week at the Dojang and is always practicing at home. She has attended numerous tournaments including the World Cup in 2013 where she won a Bronze medal in patterns. She has plans on attending several tournaments this year. Her dream is to become a black belt by the time she is 13 and will help teach. The program allows us to pay for class registrations and helps with tournament fees.” - Tanya Sasyniuk



WAHL FAMILY

“Joanna was able to play “Jane” in a production of “Tarzan”, and also performed in the Calgary Youth Singers performance of “Thoroughly Modern Millie” this summer. Joanna and her parents, Dan and Crystal have benefitted greatly by the funding from Support for Champions. Voice lessons are costly, and our income has decreased significantly with the progression of Dan’s disease. We are so grateful for this program. What a wonderful way to acknowledge that ALS affects not only the one directly affected, but also the family. Thank you so much for making our journey easier and less stressful.” - Crystal Wahl

Continued on next page



MARIQ FAMILY

“Michael said that he enjoyed the Kaye Edmonton Clinic. He couldn’t believe that it was such a big clinic, because we have a small health centre. He couldn’t believe all the many staff; he said they were all friendly. The best part of his trip was West Edmonton Mall. He enjoyed all the rides he went on and he enjoyed skating on the ice rink in the middle of the summer. He also enjoyed elevator and escalator rides, which we don’t have in Gjoa Haven. He couldn’t believe the low cost of prices in Edmonton and he wished that living up north was cheap like down south. He also couldn’t believe all the traffic because we live in an isolated area where the population is about 1250-1500.” - Pauline Mariq

SAKAGUCHI FAMILY

“When I’m pitching and get a strike out, or a base hit.” - Kai Sakaguchi



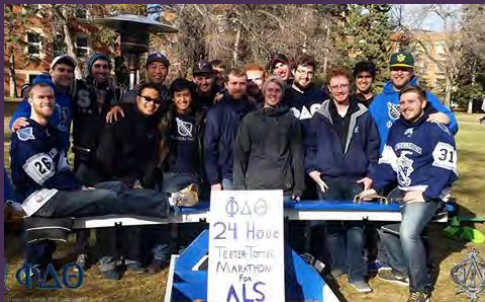
“It’s fun. It’s what we do ‘cause our dad played when he was young.” - Kyo Sakaguchi

Any Albertan age 18 and under who currently has, or has had, a parent with ALS is eligible for the program. The parent must be registered with the ALS Society of Alberta. Exact deadlines for the Support for Champions program change every year. The ALS Society of Alberta is dedicated to ‘making each day the best possible day for people living with and affected by ALS.’ This is just one more step in working towards this goal. Please contact the Society for more information.

ALS Society Events

Lethbridge WALK for ALS

Lethbridge hosted its fifth annual WALK for ALS on September 20 in Henderson Lake Park. Over \$26,000 was raised for client support services and national research. Thank you to Amber Standen for coordinating the WALK, as well as to all participants, volunteers and sponsors!



24-Hour Teeter Totter Marathon

The Phi Delta Theta fraternity from hosted their third annual teeter totter marathon in support of ALS. The fraternity brothers teeter tottered for 24 hours straight on the University of Alberta campus to raise funds and awareness about ALS! The brothers managed to raise over \$5,900! Congratulations and thank you to all participants!

Rooftop Camp-out for ALS

The Lloydminster Fire Department braved the **freezing** weather and camped out on the roof of the fire hall!

Citizens of the town donated to the ALS cause in order to convince the firefighters to come down. This event raised over \$19,000 for the ALS Society of Alberta! Thank you to the fire department for participating in this creative endeavour, and to everyone who donated!



Ethan Allen Tablescape Auction

Ethan Allen partnered with the ALS Society of Alberta over the month of December to raise money through a table dressing auction. Designers at the store created glamorous holiday-themed spreads, shared them online, and monitored a silent auction. All proceeds from this event will be donated to the ALS Society of Alberta, in memory of Pete Matthews. Thank you to Bill, Doug, Katie, the Ethan Allen - Calgary team, and to those who participated in the auction!

Judy Schweitzer ALS Curl for a Cure

On November 8, the fifth annual Judy Schweitzer ALS Curl for a Cure took place at the Michener Hill Curling Club! Carrie Mello began the Funspeil in honour of her mother, Judy, who passed away from ALS last year. Judy was passionate about curling, leading Carrie, along with friends and family, to begin an annual fundraising event. Thank you to all participants and volunteers!

Upcoming Events

Songs for Ken

February 14th, 2015

Empress Theatre, Fort MacLeod

To purchase tickets or for more information

Call 403-553-4404 or toll-free 1-800-540-9229

or online at empresstheatre.ab.ca

Edmonton Casino

March 18th-19th, 2015

Century Casino

Currently looking for volunteers

If interested, contact Brenda at SocietyNorth@alsab.ca

or at 780-487-0754



2015 WALK for ALS



With the help of our fabulous WALK Coordinators, we have begun the planning process for 2015! The ALS Society of Alberta will be hosting twelve WALKS for ALS. We are very excited to announce that St. Albert will be hosting its first WALK! The WALKs will span from May to September.

Barrhead

May 23, 2015

BarrheadWALK@alsab.ca

Edmonton

June 13, 2015

EdmontonWALK@alsab.ca

Red Deer

June 20, 2015

RedDeerWALK@alsab.ca

Camrose

June 27, 2015

CamroseWALK@alsab.ca

Hinton

June 21, 2015

HintonWALK@alsab.ca

Spruce Grove

June 6, 2015

SpruceGroveWALK@alsab.ca

Cold Lake

June 6, 2015

ColdLakeWALK@alsab.ca

Lethbridge

September 13, 2015

LethbridgeWALK@alsab.ca

St. Albert

May 30, 2015

Stalbertwalk@alsab.ca

DeBolt

August 15, 2015

DeBoltWALK@alsab.ca

Peace District

TBA

PeaceDistrictWALK@alsab.ca

Vegreville

August 22, 2015

VegrevilleWALK@alsab.ca

Check out our website for additional information and updates!

Support Groups

All Support Groups and Information Sessions are provided free of charge. They are offered in casual group settings that provide everyone with an opportunity to share their experiences, information and support. Please note that groups may be cancelled due to inclement weather - be sure to take down the contact information below.

ALS Support Group

These groups provide support to people living with ALS, their spouses, significant others, friends and families. It gives individuals the opportunity to meet others on the ALS journey, share challenges and solutions, have some fun and socialize.

ALS Family & Spousal Support Group

These warm and casual groups are for people who have lived with, or are currently living with someone affected by ALS.

Staying in Touch

This group was created for those who have lost someone to ALS.

PLS and Family Support Group

For people living with and affected by PLS.

Lethbridge

ALS Support Group

Dates: Last Friday of every month

Time: 2:00 p.m.

Place: North Bridge Seniors Centre
1904 13 Avenue N

Contact Janice at 403-393-2663
or email Janice@alsab.ca for more
information.

Red Deer

ALS Support Group

Dates: Every other month

Time: 1:00 p.m. – 3:00 p.m.

Place: MS Society Office
#105 4807 50 Avenue

ALS Family & Spousal Support Group

Dates: Every third Thursday of the
month

Time: 1:00 p.m. – 3:00 p.m.

Contact Carla at 403-357-4791
or email Carla@alsab.ca for more
information.

Leduc

ALS Support Group

Dates: Jan 19

Feb 16

March 16

Time: 11:30 a.m. – 1:30 p.m.

Place: Karunia House

Contact Brandee at 780-707-0381
or email Brandee@alsab.ca for more
information or to register.

Calgary

Staying in Touch

Dates: Jan 5

March 9

Time: 6:30 p.m. – 8:30 p.m.

Place: ALS Society Provincial Office

Contact Megan at 403-620-1358 or
email Megan@alsab.ca if you are
interested in attending or for more
details.

Edmonton

ALS Support Group

Dates: Dec 16

Jan 20

Feb 17

Mar 17

Time: 1:30 p.m. – 3:00 p.m.

Place: ALS Society Edmonton Office

Staying in Touch

Dates: Dec 18

Jan 22

Feb 19

March 19

Time: 1:30 p.m. – 3:00 p.m.

Place: ALS Society Edmonton Office

Contact Christy at 780-293-6053 or
email Christy@alsab.ca if you are
interested in attending or for more
details.

Calgary

ALS Support Group

Dates: Jan 24

Feb 21

March 21

Time: 1:30 p.m. – 3:30 p.m.

Place: Rotary Challenger Park
Canada Alberta Century
Field House
3688 48 Avenue NE

ALS Family & Spousal Support Group

Dates: Jan 29

Feb 19

March 19

Time: 6:30 p.m. – 8:30 p.m.

Place: 8211 Churchill Drive SW

Contact Jane at 403-714-8211 or
email Jane@alsab.ca for more
information on Calgary's ALS
support groups.

PLS and Family Support Group

Dates: Last Monday of every month

Time: 1 p.m. – 3 p.m.

Place: North Hill Mall condo complex
1718 14 Ave NW

Contact Megan at 403-620-1358 or
email Megan@alsab.ca if you are
interested in attending or for more
details.

#IceBucketChallenge Photos!



Howie Sniderman



MTE Logistix Management Inc.



Alberta Ballet



Cattlemans Association



Spartan Controls



Jason Skehar, Bonavista Energy



John Tuckwell



*The Honourable Rona Ambrose,
Minister of Health*



Alan Pentney



Reid Fiest



Ian White



Ryan Jespersen



Dr. Wendy Johnston



Wendy Crewson



Dr. Lawrence Korngut



Richard McBride

Kyle Ruppe

Riegert Family



Bantam Hockey

Babes on Blades

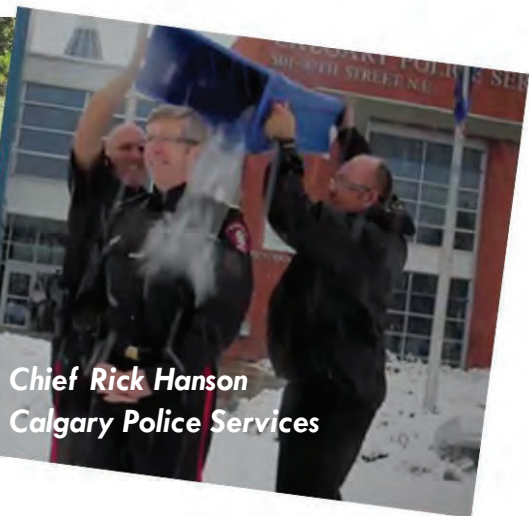
Coach Huff - Calgary Stampede



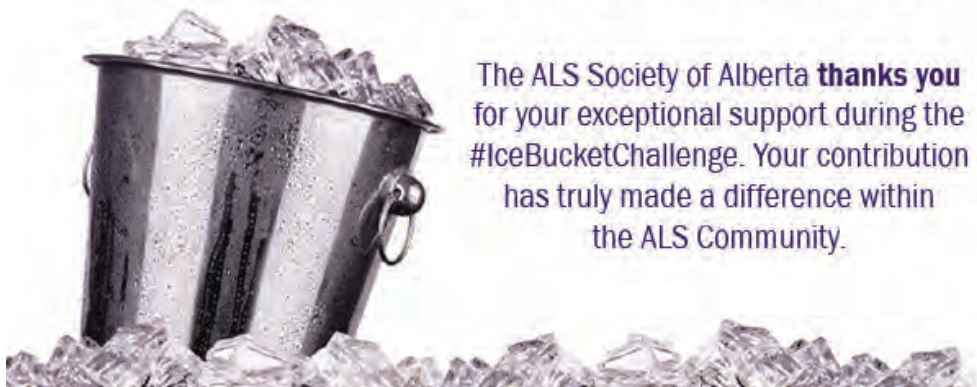
Associated Grocers

Morrison Homes

One Cycle Spin Studio



A bucket full of thanks



The ALS Society of Alberta **thinks you** for your exceptional support during the #IceBucketChallenge. Your contribution has truly made a difference within the ALS Community.

"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."

CONNECT WITH US

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twitter.com/**ALS_AB**

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