# Prairie to Peak



A PUBLICATION OF THE ALS SOCIETY OF ALBERTA October 2019

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### Walk to End ALS

#### Lethbridge



It was an incredible morning at the Lethbridge Walk to End ALS. The walk was held on September 7 and was the final walk of the season. Shelley Thom, along with friends and family championed the Walk again this year and we thank them for all of their hard work. Over \$37,000 was raised thanks to the Lethbridge ALS community.

Congratulations to Joyce Berg for being the top fundraiser, raising over \$11,000. Thank you to everyone who participated to help make this walk such a success.



Each year at the Walks we hear and see inspiring stories of family and friends supporting their loved ones living with ALS and those who have lived with ALS. This year at the Lethbridge Walk to End ALS, we were shown the tremendous support clients receive from their families even when they are not able to attend the walk in person to show their support. Linda Cross has family living across the country, from Cape Breton to Fort McMurray and in between. This summer when Linda's family had gathered in Cape Breton, they made their own Team Linda t-shirts and huddled for a photo. Although they were unable to attend the walk with Linda in Lethbridge, they were able to show her their love and support.

With the 2019 walk season wrapped up we would like to thank all of the Walk Coordinators, volunteers, donors, participants and sponsors who make the Walks such a success. Funds raised through the Walks directly impact services for people living with and affected by ALS. In Alberta, funds go toward the equipment loan program, support groups, home visits, and support for children through the Support for Champions program. Funds also go to support ongoing ALS research through the National Research Program.

### **Faces of ALS**

The Faces of ALS banners are displayed at events to honour clients. If you would like to be on the banner or if you have a loved one that would like to be on the banner, please contact Marie at (403)228-3857.



# 5th Anniversary of the Ice Bucket Challenge



Five years ago, the ALS Community was given an amazing gift. The ALS Ice Bucket Challenge went viral, forever changing the landscape of ALS awareness and research in Canada. In Alberta, a remarkable \$2.8 million was raised, with \$2 million allocated to national ALS research, and \$800,000 remaining in the province for client support services and equipment.

Since 2014, the Society has been able to replace old pieces of equipment, invest in new technologies and started building an Education Program, meant to educate frontline staff and rural communities about caring for someone living with ALS. Thank you to everyone who supported the Ice Bucket Challenge.

### **Thank You!**

#### **Sponsor Energy**



Thank you to Sponsor Energy for the donation of \$4,400! This donation will go a long way to help support people living with ALS. We would also like to thank the customers of Sponsor Energy for choosing the ALS Society of Alberta as a community partner.

#### Papa John's Pizza



Thank you Farhan Lakhani and Pulkit Arora of Papa John's Pizza for your donations of over \$600. Farhan and Pulkit own six Papa John's Pizza locations that participated in a promotion to raise funds for the ALS Society of Alberta during the month of August. We are honoured you chose the Society for this promotion.

#### **Alliance Equipment**



Thank you Alliance Equipment for the donation of \$1000. Alliance Equipment held a Customer Appreciation Day and donated the proceeds to the Society. We are so appreciative of your support.

### **Community Events**



#### Quonset Days 10th Anniversary

Quonset Days "greatest outdoor party on dirt" took place on July 19-20 in Seven Persons. The event started as a tribute to Peter Biemans, who passed away in 2009 after a hard fought battle with ALS. Thank you to the Biemans family (Janet, Trevor, Brianne, Traci & Brandon) for your continued dedication and support to the ALS cause. An astounding \$65,000 was raised!



#### Monarch Roofing

Monarch Exterior and Roofing held their Customer Appreciation Day in Edmonton on July 26th and chose the ALS Society of Alberta as a recipient of funds! Thank you so much to Errol Schalm for donating over \$7,000 to the Society and for your ongoing support!



#### Songs For Ken

The fifth anniversary for Songs for Ken hosted by John Wort Hannam played to a packed house on September 27th in Calgary. John and his friends, T. Buckley, Emily Triggs, Mike Stack, Jesse Dollimont and the House Band Extraordinaire earned a standing ovation for their exceptional entertainment. The remarkable artist, Randall Wiebe did a live portrait during the concert. This amazing night was in support of the ALS Society of Alberta. Thank you John!



#### Stitchin' for Support

Sylvia Tensfeldt is living with ALS but she hasn't let her diagnosis prevent her from doing her favorite things including cross-stitching. Sylvia has been working on an embroidery project and raising funds for the Society. The cross-stitch project contains approximately 40,000 stitches and she has almost completed the project. To date, Sylvia has raised over \$2,400



Skip Hayden Memorial Golf Tournament

The Skip Hayden Memorial Golf Tournament took place on August 14 in Olds. The tournament is held by the Alberta Association of Recreational Facility Personnel. This is the third year the tournament has partnered with the Society to raise awareness and funds through a 50/50 draw.



#### Howard Smith Memorial Roping

Congratulations and thank you to the Smith family for hosting the 19th Annual Howard Smith Memorial Team Roping. They raised an amazing \$3,585! Another successful event with exceptional volunteers and donations from Sundre Dental Clinic, Milestone Oilfield, Dougan's Farm & Feed Supply, and Blackhurst Oilfield. The winners of this year's Team Roping were Jordan Richardson and Bill Manness. Thank you to all the ropers who generously donated their prize money to the ALS Society.

# **Community Events**



#### Kai's Birthday Bash

Kai's first birthday was celebrated with a splash! The birthday celebration was also a fundraiser for the Society which included family and friends participating in the Ice Bucket Challenge each day during the month of August. Thank you Ashley, Brooklyn, Madison and Kai for helping raise awareness and funds, we truly appreciate your support.



#### Village Fashions "It's in the Bag" Event

Village Fashions in Stony Plain created their "It's in the Bag" fundraiser to honour their friend, Kevin Walshe. With a minimum donation of \$20, customers receive a reusable bag that entitles them to fill the bag on select Saturdays with 20% savings. The next and final Saturday is November 30th, 2019!



Phi Delta Teeter Totter Marathon

The Phi Delta Theta Fraternity at the University of Alberta hosted their 7th annual 24-hour teeter totter marathon for ALS on September 25th & 26th. This event has raised a great deal of awareness among the university community since its inception. Thank you to Cody and the rest of the fraternity for your hard work!



#### Stanley Carlstad Memorial Ball Tournament The 10th Annual Stanley Carlstad Memorial Ball Tournament took place in June, and this annual slowpitch tournament raised an incredible \$15,832! A warm thank you goes to Trudy Roy and the Carlstad family for all their hard work and dedication in making this event a success!



#### Swing for ALS

The Annual Swing for ALS Golf Tournament in Cold Lake raised over \$6,000 this year on July 6th! Thank you to Leon Lefebvre and Wendy Reed for your consistent hard work in planning this tournament, and to all the other volunteers, supporters and participants!



Parrot Head Club Charity Golf Tournament

The Calgary Parrot Head Club held their annual golf tournament on September 7. This year, the Club chose the ALS Society of Alberta as a recipient of funds from the tournament. Thank you to The Calgary Parrot Head Club for organizing such a great tournament and to Tops Pizza and Steakhouse (South) for sponsoring the event. The tournament raised over \$1,500.

# **Community Events**



#### Oktoberfest

Danny Getzlaf brought Oktoberfest back to Morinville and turned it into a fundraiser to support the ALS cause. Hundreds of people participated in the 12 hour fun filled day with the night ending with dancing to the Emeralds.

Thank you Danny for reminding us to live and celebrate each day.

#### **Facebook Fundraisers**

The ALS Society of Alberta is so grateful for the support we have received recently through Facebook fundraisers. We have also received many questions about fundraisers set up on Facebook and the different giving options. Facebook can be a quick and easy way to raise money and engage your network of friends and family. The Society does not receive notification when fundraisers are set up and we ask that if you have set one up to please let us know as we would like to thank you and cheer you on for your fundraising. We thank you so much for choosing to support the ALS Society of Alberta.

Here are some helpful facts about Facebook fundraisers.

- Any one can create a fundraiser for the ALS Society of Alberta by searching for "ALS Society of Alberta" from the list of registered charities.
- Donations are processed at no cost to the donor or to the individual who set up the fundraiser.
- Receipts are issued to the donor by email through Facebook.
- Donations are sent to the Society by Facebook through the PayPal Giving Fund.
- If you or your donors have questions about the setup, donations, receipts or refunds, you will need to contact Facebook Fundraiser Support Centre.
- The Society does not receive any contact information on the donors to your fundraiser.
- Facebook does not notify the Society when you set up a fundraiser. We hope you will inform us if you set one up, as we would like the opportunity to thank you for your support.

If you have any questions regarding Facebook fundraisers please contact Marni at marni@alsab.ca or (403)228-3857. **Did You Know...** 

Donations can be made to the Walks and Betty's Run up until December 31. We continue to raise funds for these events until the end of the year. To make your donation please visit www.alsab.ca or call (403)228-3857. All donations to Betty's Run and the Walk to End ALS have a significant impact on the services we provide to the ALS community.

# **Upcoming Events**

#### Judy Schweitzer Curl for a Cure

November 9, 2019 Mitchener Hill Curling Club - Red Deer To register contact alscurlforacure@hotmail.ca

#### Village Fashions "It's in the Bag"

November 30, 2019 - Last Day of the Event Stoney Plain, AB With a minimum \$20 donation, you will receive a reusable bag which you can fill to receive a 20% discount on everything in the bag.

For information on upcoming events please contact marni@alsab.ca



# **Volunteers Wanted**

We are actively looking for volunteers across the province. Would you like to join the organizing committee of the Walk to End ALS in Edmonton? The committee is looking for new members to assist with planning the Edmonton Walk.

If you are interested in volunteering for events please contact Marni at marni@alsab.ca or visit the volunteer section of the website at www.alsab.ca.

# **Research Update**

#### CALSNIC

Although the CALSNIC study is heading into the last couple of years, ongoing enrollment is still needed. Currently there is no test for ALS. Whereas, many other disorders are diagnosed with a blood test, x-ray or CT, the diagnosis of ALS is made in large part by ruling out other diseases that can mimic it. The Canadian ALS Neuroimaging Consortium (CALSNIC) was formed to create and evaluate new test for ALS that use advanced MRI. The CALSNIC team thanks patients, their caregivers, and family and family who have given so generously of their time to participate in the study. For more information please visit www.calsnic.org.

#### CAPTURE ALS

A special workshop was held at the Montreal Neurological Institute on September 19th where various scientists and clinicians identified the most important needs for ALS research, the most important gaps to advance knowledge of ALS, and the resources required to accelerate ALS research in Canada. The discussion helped to develop the upcoming CAPTURE ALS project.

The Comprehensive Analysis Platform To Understand, Remedy, and Eliminate (CAPTURE) ALS is an initiative by Canadian investigators that will extend CALSNIC to include collection of blood, CSF, urine, and post-mortem tissue. Such a biobank would be a critical resource for researchers to understand basic mechanisms and develop new diagnostic tests, towards improving our understanding of ALS and finding effective treatments.

#### U of A Research Update

The ALS Talk Project will include focus groups for people diagnosed with ALS and focus groups for family members/caregivers. Participants will share and discuss their experience talking to health care professionals about the ALS diagnosis, treatment and advanced care planning. Your input will help improve communication between health professionals and people living with ALS and their families. People can participate at their convenience and from their own computers/electronic devices. A discussion topic and questions will be posted every two weeks. There will be eight discussion topics. The focus group will begin in November. If you are interested, study details and contact information can be found here: https://tinyurl. com/UA-ALS-talk.

#### U of C Research Update

Dr. Pfeffer's lab is collaborating with Dr. Korngut and the ALS Clinic in Calgary to identify biomarkers associated with ALS, by studying noncoding RNA expression in blood, using a similar design to a previous study from Dr. Pfeffer's lab (https://doi. org/10.1016/j.msard.2019.101407). Drs Pfeffer, Korngut and Nguyen are collaborating on a study to use DNA sequencing to identify the microbiome content of saliva from ALS patients and controls, and to build on prior studies suggesting the microbiome may have a role in the development and severity of ALS.

### 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 the 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 AND SPOUSAL SUPPORT GROUP

These groups are for people who have or are currently supporting someone affected by ALS.

#### STAYING IN TOUCH

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

#### PLS & KENNEDY'S

For people living with and affected by PLS, Kennedy's and other neuromuscular disorders.

#### Calgary

ALS Support Group

Dates: Oct. 10, Nov. 14, Dec. 12

Time: 1 p.m. - 3 p.m. Place: Bridgeland Riverside Community Association 917 Centre Ave NE Contact: 403-815-1567 |Rob@alsab.ca

#### ALS Family Support Group

Dates: Oct. 28, Nov. 25 Time: 1 p.m. - 3 p.m. Place: ALS Society of Alberta Calgary Office 7874 10 St. NE Contact: 403-815-1567 | Rob@alsab.ca

#### Staying in Touch

Dates: Dec. 2 Time: 1:00 p.m. - 3:00 p.m. Place: ALS Society Calgary Office Contact: 403-815-1567 | Rob@alsab.ca

#### PLS & Kennedy's Group

Dates: Oct. 28, Nov. 25 Time: 1 p.m. - 3 p.m. Place: North Hill Mall Condo Complex | 1718 14 Ave NW Contact: 403-620-1358 | Leslie@alsab.ca

#### Edmonton

ALS Support Group Dates: Oct. 15, Nov. 19, Dec. 17 Time: 1:30 p.m. - 3 p.m. Place: ALS Society Edmonton Office Contact: 780-487-0754 | SocietyNorth@alsab.ca

#### ALS Caregivers Support Group

Dates: Oct. 15, Nov. 19, Dec. 17 Time: 1:30 p.m. - 3 p.m. Place: ALS Society Edmonton Office Contact: 780-487-0754 | SocietyNorth@alsab.ca

#### PLS & Kennedy's Group

Dates: Nov. 15, Dec. 20 Time: 2 p.m. - 3:30 p.m. Place: ALS Society Edmonton Office Contact: 780-487-0754 | SocietyNorth@alsab.ca

#### Staying in Touch

Dates: Nov. 15 Time: 11:30 a.m. - 1 p.m. Place: ALS Society Edmonton Office Contact: 780-487-0754 | SocietyNorth@alsab.ca

#### St. Albert

ALS & PLS Group Dates: Oct. 11, Nov. 1, Dec. 6 Time: 2 p.m. - 3:30 p.m. Place: Servus Credit Union Place, Morinville Room Contact: 780-487-0754 | SocietyNorth@alsab.ca

#### Lethbridge

ALS Support Group Dates: Oct. 25, Nov. 25 Time: 2 - 3:30 p.m. Place: Nord-Bridge Seniors Centre Contact: 403-620-1358 | Leslie@alsab.ca



"Our mission is to make each day the best possible day for people living with and affected by ALS."

### CONTACT US

#### **PROVINCIAL OFFICE**

7874 10 St NE Calgary, AB T2E 8W1 www.alsab.ca | info@alsab.ca (403) 228-3857 | Fax (403) 228-7752 Toll Free: 1-888-309-1111

#### EDMONTON OFFICE

5418 97 Street NW Edmonton, AB T6E 5C1 societynorth@alsab.ca (780) 487-0754 | Fax (780) 486-3604 Toll Free: 1-866-447-0754

### PLEASE CONSIDER MAKING A MONTHLY GIFT

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). OR

charge my monthly donation of \$\_\_\_\_\_ to my credit card

at the beginning / middle of each month. (Please call (403)228-3857 to set up credit card donations).

Date	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 ( <i>Please call (403)228-3857 to set up credit card donations</i> ).		
Please send my charitable tax receipt to:		
Last Name	First Name	
Address		
City/Town	Province	Postal Code

Phone \_\_\_\_\_\_ E-Mail \_\_\_\_\_\_

### Please return this form to the ALS Society of Alberta's Provincial Office. Your gift will help us to make each day the best possible for those living with and affected by ALS.

PRIVACY STATEMENT: Your personal information will not be traded, sold, or shared without knowledge or consent. For more information, please call the ALS Society of Alberta's Provincial Office.

The Society aims to raise \$1,846,988 in donations with fundraising costs of approximately 12% in expenses.