

# Prairie to Peak

A PUBLICATION OF THE ALS SOCIETY OF ALBERTA  
AUGUST 2018



## IN THIS ISSUE

1. ALS Awareness Month:  
Making it Possible
2. Betty's Run for ALS
3. WALK for ALS
4. Community Events
5. Upcoming Events
6. Research Update
7. Support Groups





# MAKING IT POSSIBLE

## ALS AWARENESS MONTH

"Making it Possible" represents the ALS Society of Alberta's mission to make each day the best possible day for those living with and affected by ALS. Each year, during the month of June (ALS Awareness Month) the Society encourages the ALS community to share stories of how they are able to make moments and memories possible with the help of their friends, families and caregivers. This year, 25 stories were collected and shared on the Society's social media to help spread awareness and garner support of the Society's mission.





**MAKING MEMORIES AT THE ZOO**

Shirley's story helped to kick off ALS Awareness Month. The client services team joined Shirley at the zoo so she could see the monumental panda exhibit. She used a tilt manual chair that could allow her to see the pandas safely and comfortably.



**ORFINO WEEKLY POKER NIGHT**

"My brother Glenn brought one of his poker tables and 6 to 9 guys come and we play Texas Hold-em for a couple of hours once a week. I've programmed my computer with poker lingo and sayings that make the guys laugh."



**DEBOGORSKI WEDDING**

"On April 28, 2018, around 10 months after Andrew's diagnosis, we married each other in the most beautiful church ceremony, in front of our dearest loved ones and supportive members of the community."

**MAKING IT POSSIBLE WITH GLEN JARBEAU**

"Three months ago I told my brother and sister in law I didn't think I would make it to the wedding, but my spirit is strong ... and I got there! A big team of people made it possible for me to have the equipment needed to attend my brother's wedding in Calgary. I cried like a baby at the wedding and made everyone else cry too. Being with the people I love is kind of like a long goodbye or a long farewell."

Glen demonstrates a wonderful commitment to celebrating life and seizing every opportunity. He has been an exceptional advocate for the ALS Society of Alberta, attending the legislature to advocate for the best possible care and participating in media interviews. In June, Glen was interviewed by CBC Radio Active Edmonton to talk about his journey with ALS and how he continues #MakingitPossible





# 22nd Annual Betty's Run for ALS



The 22nd annual Betty's Run for ALS took place on Sunday, June 10 at 9 a.m. in North Glenmore Park. Over the past 22 years, Betty's Run for ALS has raised over \$7 million for client support services and research. This event aims to celebrate, promote and channel hope to those affected with ALS, along with their families and friends.



Betty's Run for ALS began when Calgarian Betty Norman unselfishly donated her time and efforts to raise awareness about the disease despite her own battle with ALS. Her story has now stemmed into support from over 40,000 people. Of funds raised, 60 per cent remain in Alberta for client support services, including the Equipment Loan Program, support groups, home visits, and support for youth. The remaining 40 per cent are invested into the most promising ALS research.



Each year, the Betty's Run for ALS planning committee chooses an Ambassador to show the public what it is like to live with the disease. The ALS Society of Alberta was proud to welcome Wayne Thomas as the 2018 Betty's Run for ALS Ambassador. Wayne is a dedicated member of the Alliance Pipeline Team, and has generously donated his time to raise awareness about ALS.

"From a personal perspective, this diagnosis has been a glaring reminder for me that we all have to savour life more and live it to the fullest. I have had a great life so far, and any experience I have going forward will be counted as a blessing not a right," said Wayne. "Supporting Betty's Run is a great example of how we can all get involved and I am honoured to be part of it."



This year's event raised over \$486,000, far exceeding the fundraising goal of \$450,000. The ALS Society of Alberta would like to thank Ambassador Wayne Thomas for all of his dedication in raising awareness for the Society. The Society would also like to thank Mayor Naheed Nenshi, the 2018 Betty's Run for ALS Planning Committee, and all sponsors, volunteers, donors and supporters. This event has continued to make a tremendous impact in the community.



# PJ Impact



The 2018 Betty's Run for ALS Top Team Fundraiser was PJ Impact, who raised an incredible \$100,000+ for the event. The team rallied together to remember Patrick O'Connor and his journey with ALS. The team sported their custom maroon shirts and successfully broke Betty's Run for ALS fundraising records. The ALS Society of Alberta and the 2018 Betty's Run for ALS planning committee would like to extend its sincerest thanks for the incredible commitment and generosity displayed by PJ Impact. This remarkable fundraising total will make a significant impact in the lives of people living with and affected by ALS.

# Red Deer WALK for ALS

This year marked the 15th anniversary of the Red Deer WALK for ALS! It was a beautiful sunny day on June 16 in Kiwanis Picnic Park, and over 200 members of the ALS community gathered to raise funds and awareness for ALS client support services and research. Nearly \$100,000 was raised through this incredible event!

Red Deer WALK for ALS Coordinators Michelle Parker and Deborah Hansen organized a butterfly release to kick off the WALK, where each family released a butterfly to symbolize their loved one. The WALK was also followed by a BBQ, speeches and music by Jim Said.

Thank you to the Red Deer WALK for ALS planning committee for all of your hard work in planning this event, to Jonathan Strome for taking photographs, and to everyone who donated, participated, sponsored or volunteered their time to help make this event such a success.





# 2018 Edmonton WALK for ALS

It was an incredibly inspiring day at the 2018 Edmonton WALK for ALS on June 9. Over 1,000 people gathered in William Hawrelak Park to celebrate the lives of people affected by ALS in Alberta, and to raise funds for client support and research.

The Society was honoured to have Tamis and Perry Rombough share words on behalf of the WALK Ambassador, Adam Rombough:

“Even though this is a horrible disease, I am not focusing on the negatives, I am choosing to focus on all of the positive blessings that this has brought into my life and I hope that you will too. Some of these blessings include: retiring at age 32, planning trips to see and experience the world, having the opportunity to tell my family how much they mean to me and how much I love all of you.”

Adam shared these words in a Facebook post after his diagnosis. He passed away just before the WALK in May.

Thank you to all volunteers, donors, supporters, participants and sponsors for your dedication to the Edmonton WALK for ALS. The ALS Society of Alberta would also like to thank the 2018 Edmonton WALK for ALS planning committee for the countless hours they dedicated to planning this incredible event.

The 2018 Edmonton WALK for ALS exceeded its fundraising goal of \$380,000, and has almost reached the \$400,000 mark. It is incredible to see the support pour in from the community, and to channel hope for a future without this devastating disease.





## Danny Getzlaf Community Spirit



Danny Getzlaf has spearheaded some incredible contributions to ALS awareness and fundraising in Morinville and beyond. Danny hosted a number of initiatives in support of the Edmonton WALK for ALS, including button sales, BBQs, raffles, silent auctions, media interviews, meat draws and more. On the first weekend in June, Danny and his community raised over \$11,500 through two different events! The support that Danny has garnered in his community has made such a significant impact for the Society, and has raised a tremendous amount of awareness.

Danny coordinated buses to transport folks from Morinville to the Edmonton WALK for ALS in June. His team successfully raised over \$37,000, far surpassing his goal of \$30,000. This contribution will greatly aid in the Society's mission of making each day the best possible day for people living with and affected by ALS.

The Society would like to extend its sincerest thanks to Danny, his wife Linda, and all of their family and friends!

## Drayton Valley WALK for ALS



The first annual Drayton Valley WALK for ALS took place on Saturday, June 16 in West Valley Lion's Park. Over \$27,000 was raised to support client services and research, which was an incredible achievement by a hard working group of volunteers and organizers.

Melanie and Marcie Pruden and Nicole Tymchak worked around the clock to make this event a success. They spent the year raising awareness in their community, organizing community fundraisers, doing media interviews, posting on social media and obtaining sponsorship for every part of the WALK.



Thank you to Melanie, Marcie and Nicole for all of your hard work in the planning of this event and all the volunteers and participants who came out to support the event. The ALS Society is excited to watch this event grow and is positive it will continue to be a great success.





### Cold Lake WALK for ALS

Cold Lake kicked off the 2018 WALK for ALS season on June 2 and raised over \$10,000! Pat and Michelle Feduniak, along with their family and friends, have been dedicated volunteers and supporters of the ALS Society of Alberta for many years. Without their unwavering support, the Cold Lake WALK for ALS would not be possible. Thank you to everyone who came together to channel hope for a future without ALS.



### Grande Prairie WALK for ALS

The Grande Prairie WALK for ALS raised over \$7,500 this year! This inspiring and successful WALK would not be possible without the hard work of Mandy Van Dresar, and her family and friends. Mandy has worked tirelessly over the years to support the ALS cause in the Grande Prairie community, and has raised a great deal of awareness to help fight against this disease. Thank you for all that you do, Mandy!



### Peace District WALK for ALS

The Peace District WALK for ALS had a record-breaking year, with over \$16,000 raised! This event is coordinated by Johanna Downing, her family and friends, and they continue to raise a great deal of awareness across the Peace District and beyond. Thank you to everyone who gathered to support those affected by ALS in Peace River, and to all who donated, sponsored and volunteered. Your support makes a direct impact in the Alberta ALS community.



### Camrose WALK for ALS

The Camrose WALK for ALS took place in Mirror Lake Park on June 23. Over \$16,000 was raised thanks to the dedication and support from the Camrose ALS community. Thank you to all who attended to celebrate the lives of those affected by ALS, and for those who volunteered their time to help organize the event. The Society could not do what it does without the support of the WALK for ALS community!



### Fort McMurray WALK for ALS

The third annual Fort McMurray WALK for ALS took place in Birchwood Trails on June 10. WALK Coordinator Paul Downey has worked tirelessly in his community to raise funds and awareness for ALS. This year, he helped break fundraising records and raised over \$8,000! Thank you to everyone who sponsored, donated, volunteered or participated in the Fort McMurray WALK for ALS!



### Valley Ridge WALK for ALS

The Valley Ridge WALK for ALS far exceeded their \$2,500 fundraising goal and raised \$3,800 for the ALS Society of Alberta! Thank you to the Valley Ridge Family Physicians for organizing this incredible event, and thank you to everyone who participated and helped make this WALK such a huge success!



# Community events



## ALS BBQ Fundraiser at YYC

The Calgary Airport Authority and HMS Host gathered on June 15 to raise awareness and funds for ALS. The event raised nearly \$500 for the ALS Society of Alberta!



## Nancy McLennan Golf Tournament

The second annual Nancy McLennan Golf Tournament took place on June 21 at the Derrick Golf Course. Thank you to Michelle Berry for planning this incredible event.



## Healthcare Solutions South Grand Opening

The Healthcare Solutions Grand Opening chose the Society as its charity of choice and raised \$600 through an opening sale on June 23!



## Stanley Carlstad Memorial Ball Tournament

The annual Stanley Carlstad Memorial Ball Tournament raised over \$18,000! This incredible fundraiser continues to garner a tremendous amount of support in Bear Canyon.



## Boilermakers Lodge 146 Golf Tournament

This is the second year the Boilermakers have raised funds for the ALS Society of Alberta through a raffle and silent auction. Over \$4,000 was raised for the Society this year! Thank you to the Executive Board for choosing the Society.



## Monarch Exterior & Roofing Customer Appreciation Day

Monarch Exterior and Roofing held a silent auction on July 27 in Edmonton, with 50 per cent of funds raised donated to the ALS Society of Alberta. Thank you for your continued support!



# Community events



## Quonset Days

The ninth annual Quonset Days took place on July 20 - 21 in Seven Persons. Organizers are calling this year's event the biggest yet. Thank you to the Biemans family for all of your hard work in planning this event. 2018 broke previous records and raised \$87,000 for the ALS Society!



## Howard Smith Memorial Roping

For nearly 20 years, the Smith family has organized a calf roping event in memory of Howard Smith who lived with ALS. This year, they raised over \$2,400 for the ALS Society of Alberta after winners generously donated their prize money. Thank you to the Smith family for your continued support.



## RFP Skip Hayden Memorial Golf Tournament

This year was the second time the Society partnered with the Skip Hayden Memorial Golf tournament, and was able to raise \$218 through the 50/50! Thank you to RFP!



## Saz's Soldiers ALS Charity Golf Tournament

The seventh annual Saz's Soldiers took place on August 10 in Beaumont at the Coloniale Golf Course. Fifty per cent of funds raised were donated to the ALS Society!



## Strawberry Social

Chelsea Tipping organized a strawberry social on July 21 in St. Albert at Privada Wine and Tapas. Funds were raised through raffle ticket sales and a 50/50! Fundraising totals will be announced soon!



## Claire and Adam's Awesome Lemonade Stand

Claire and Adam worked tirelessly selling lemonade in support of Team A-Bomb through the Edmonton WALK for ALS. The hardworking fundraisers raised \$1,295.18 for the Edmonton WALK for ALS!



# Upcoming events

**The ALS Society of Alberta**

## 1 Golf 4 Gurdev

### CHARITY GOLF TOURNAMENT

**In Support of ALS**

Whether you are an avid golfer, weekend warrior or tournament enthusiast, this charity best ball tournament will be sure to make for a great day!

You can play as an individual or put together a team. Cost for the tournament is **\$165**, which includes 18 holes of golf, cart and delicious dinner.

We are also looking for hole sponsors. For only **\$500**, your business will be recognized on one of the beautiful tee boxes, during the dinner ceremonies and in our flyer that will be placed at each table. You will also receive 2 entry fees as part of the package.

What could be better than playing a round of golf and having a delicious dinner, all while supporting a great cause.

For information or to reserve your spot, call Nivi Uppal, Insurance Broker at Costen Insurance - 403-389-2489 or email [nivi@costeninsurance.com](mailto:nivi@costeninsurance.com).

**Gurdev Singh Dhillon**  
was diagnosed with ALS in the summer of 2013 and after a courageous battle, passed away on June 7, 2015

**Thursday, September 6, 2018 ~ 1:00 P.M.**  
**Cottonwood Golf and Country Club**

### AOC Golf Tournament

Aug. 28, 2018  
Red Tail Landing Golf Club

### Big Drew's Big Ride

Sept. 8, 2018  
Come join for the fifth and final ride along the Legacy Trail in support of the ALS Society of Alberta.

### Swing for ALS Golf Tournament

Sept. 15, 2018  
Grand Centre Golf Course, Cold Lake

### Pickle Ball Tournament

Sept. 22, 2018  
Royal Gardens

### Leigh Reed Art Show

Oct. 6, 2018  
Pumphill Community Centre

For more information about these events, contact  
[Lisa@alsab.ca](mailto:Lisa@alsab.ca)

All proceeds will go to ALS Society of Alberta

## Garage Sale

In memory of Bob Skinner, an electrician who passed away from ALS in November 2017

**SATURDAY, SEPTEMBER 8**  
**8AM - 6PM**

6 miles North HWY 17 Lloyminster  
3.5 miles West TWP 510

Items for sale include mostly electrical equipment, wires, electrical panels, engine lifts, ladders, power tools, camping appliances and a number of other items

**The ALS Society of Alberta**

# UPCOMING WALKS FOR ALS

**Lethbridge - Saturday, September 8**

Henderson Lake Park

Registration: 10 a.m.

Kick-off: 11 a.m.

**Hinton - Sunday, September 9**

Green Square

Registration: 10 a.m.

Kick-off: 11 a.m.

Visit [www.walkforals.ca](http://www.walkforals.ca) to donate or register.



## Research update

ALS research is at a time of unprecedented advancement and hope. In June, the national ALS research program summarized some of the most significant research discoveries.

### **New insights into how mutations in the protein FUS leads to the development of ALS**

These findings open up new avenues to explore when developing treatments for FUS-linked ALS, and are of broad importance as these biological mechanisms are part of our evolving understanding of other forms of ALS as well as frontotemporal dementia (FTD).

### **A promising lead for treatment of an inherited form of ALS**

A team of researchers at the University of Liverpool has identified a possible new treatment strategy for an inherited form of ALS. Mutations in the SOD1 protein represent the second most common cause of inherited ALS. The community hopes to see a similar number of treatment options in development for all forms of ALS.

### **Researchers identify a new link between two cellular processes disrupted in ALS**

In recent years, researchers have made significant progress in identifying the various cellular pathways that are disrupted in ALS. This is important because a better understanding of the pathways involved, as well as how they interact with each other to cause ALS, is crucial to developing an effective treatment.

### **Advances in models used to study the biology of ALS**

In its early stages, medical research is often conducted using disease models (ranging from nerve cells in a dish, to worms, to mice). The use of disease models allows researchers to study the biology of the disease in ways they could not in people. In order to be useful, however, these models must accurately represent how the disease develops in the human body. In an April 2018 study, researchers described a new technique that allowed them to grow a patient's own neurons and blood vessels together outside the body for the first time.

To learn more visit [www.alsab.ca/research](http://www.alsab.ca/research)



# 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 warm and casual 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: Sept. 8, Oct. 13, Nov. 3, Dec. 1  
Time: 1:30 p.m. - 3:30 p.m.  
Place: ALS Society Calgary Office  
Contact: 403-620-1358 | Leslie@alsab.ca

### ALS Family & Spousal Support Group

Dates: Sept. 24, Oct. 29, Nov. 26  
Time: 6:30 p.m. - 8:30 p.m.  
Place: Quarry Park Library, Room #2  
108 Quarry Park Road SE  
Contact: 403-815-1567 | Rob@alsab.ca

### Staying in Touch

Dates: Oct. 1, Dec. 3  
Time: 6:30 p.m. - 8:30 p.m.  
Place: ALS Society Calgary Office  
Contact: 403-815-1567 | Rob@alsab.ca

### PLS & Kennedy's Group

Dates: Sept. 24, Oct. 29, Nov. 26  
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: Sept. 18, Oct. 16, Nov. 20  
Time: 1:30 p.m. - 3 p.m.  
Place: ALS Society Edmonton Office  
Contact: 780-487-0754 | SocietyNorth@alsab.ca

### ALS Family & Spousal Support Group

Dates: Sept. 18, Oct. 16, Nov. 20  
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: Sept. 21, Oct. 19, Nov. 16, Dec. 21  
Time: 2 p.m. - 3:30 p.m.  
Place: ALS Society Edmonton Office  
Contact: 780-487-0754 | SocietyNorth@alsab.ca

### Staying in Touch

Dates: Sept. 21, Nov. 16  
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: Sept. 7, Oct. 5, Nov. 2, Dec. 7  
Time: 2 p.m. - 4 p.m.  
Place: Servus Credit Union Place, Morinville Room  
Contact: 780-707-0381 | Brandee@alsab.ca

## Lethbridge

### ALS Support Group

Dates: Sept. 28, Oct. 19, Nov. 30  
Time: 2 - 3:30 p.m.  
Place: Nord-Bridge Seniors Centre  
Contact: 403-620-1358 | Leslie@alsab.ca

## Red Deer

### ALS Support, Family & Spousal Support Group

Dates: Sept. 15, Oct. 27, Nov. 24  
Time: 1 - 3 p.m.  
Place: MS Society Office | 105, 4807 50 Avenue  
Contact: 403-815-1567 | Rob@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

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 \_\_\_\_\_ 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:

Last Name \_\_\_\_\_ First Name \_\_\_\_\_

Address \_\_\_\_\_

City/Town \_\_\_\_\_ Province \_\_\_\_\_ Postal Code \_\_\_\_\_

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

Credit Card Information:

Select: Visa MasterCard American Express

Credit Card Number \_\_\_\_\_

Expiry Date \_\_\_\_\_ CVV# (3 digit located on back of card) \_\_\_\_\_

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.*