

# Prairie to Peak

A PUBLICATION OF THE ALS SOCIETY OF ALBERTA

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## Go Flames Go! Thank you Mikael Backlund & Frida Engstrom!



“I was lucky enough to go to a home game this season and was very surprised to receive a Flames jersey from Mikael. He is a wonderful person and is doing a lot for us who are fighting this disease. Thank you very much Mikael for all you have done”  
- Tom Eastland



Me and my family were blessed to go to one of these games and meet Mikael. Such a great guy and the work he and Frida are doing to fight this disease is incredible. Thank you again Mikael we are still talking about that game.

- Rocky Leer



## 2017 Research Contribution

The ALS Society of Alberta is proud to be the second largest donor to Canada’s national ALS research program. The ALS Society of Alberta Board presented a cheque for \$325,825 to the program last month, thanks to the incredible donors and fundraisers through the WALK for ALS and Betty’s Run for ALS. The support in this province allows Alberta to continue making a significant impact in the future of ALS research. Thank you to everyone who participates every year and helps make this annual contribution possible.

## Significant research investment made possible by Mikael Backlund and Frida Engstrom



On November 10, Mikael Backlund and fiancée Frida Engstrom generously hosted Uncorked for ALS at the Bridgette Bar in Calgary. The event helped to raise awareness and funds for ALS research in Canada.

Frida lost her mother to ALS in Sweden in 2013, and has since dedicated her time to the ALS cause. From the hockey tickets her and Mikael donate to ALS families each month, to the multitude of fundraisers they have hosted in support of the Society, they are truly an exemplary example of community passion and support.

Due to the incredible support of the event, Mikael and Frida were able to present Dr. Lawrence Korngut of the ALS and Motor Neuron Disease Clinic with a cheque for \$40,000. This significant investment will aid in the second phase of the ongoing Pimozide clinical trial that looks at a psychiatric drug that could potentially delay the progression of ALS.

A heartfelt thank you goes out to Mikael and Frida for their unwavering commitment to the ALS cause. For more information about the Pimozide trial, visit [alsab.ca/](http://alsab.ca/)

## Jane's Next Adventure



After 20 years of working with the ALS Society of Alberta in client services and support, Jane Rivest began her retirement on March 1. We will dearly miss Jane and her leadership, commitment and support to families living with and affected by ALS in Alberta. However, after years of supporting the community, it is time for Jane to do something for Jane.

Thank you to everyone who joined us on March 3 to celebrate Jane's incredible milestone. We know she will still play an integral role in Betty's Run for ALS each year, and that we will still see her often!

Thank you Jane for all that you have done for the ALS community and for the lasting impact you have made.

# 22nd Annual Betty's Run for ALS

Sunday June 10, 2018

9 a.m. in North Glenmore Park

*Each year, the Betty's Run for ALS Committee selects an Ambassador to help show the public what it is like to live with the disease. The ALS Society of Alberta is thrilled to introduce Wayne Thomas as the 2018 Betty's Run for ALS Ambassador.*



“I first noticed weakness in my left foot in 2015 while running with a friend. When it persisted and worsened over the next few months, I saw a doctor who assessed it as a probable back injury. For 2016, I did all the things you would for a back issue: an MRI, acupuncture, chiropractor and physio but still it wasn't getting better. In January 2017 with my foot becoming full-on drop-foot and it becoming difficult to walk without a leg brace, I was at a loss for answers. I went to another doctor for a second opinion and he agreed that this didn't seem normal. He recommended I have an EMG /nerve conduction test. By May it was revealed that I had significant muscle deterioration in my lower left foot and leg. After many medical tests to rule out all other possibilities, it was determined there was a high probability I had something I had not expected – a diagnosis of slow-progressing Amyotrophic Lateral Sclerosis or ALS.

Initially, I was devastated. After the grief and shock subsided, and with the support of my wife Joanna, family and friends, I got on with facing the disease head-on. I continued to work, exercise, travel and with the help of Joanna, researched various known treatments to further slow the disease. Through an ALS forum, she discovered a drug called Radicava / Edaravone that was invented in Japan and originally targeted for stroke sufferers. With her at my side, we travelled to Japan in the fall where I spent five weeks receiving the infusions with the intent to carry on with them back home. In addition, I have signed up in Canada for other clinical trials of medications being tested to treat ALS.

I am hoping that sharing my story will help shine more light on this disease. I want everyone to know that ALS is a severely underfunded illness. The support of fundraisers such as Betty's Run, however, have accelerated the number of promising investments being made into national ALS research. The ALS Society needs our support so that not only the patients already diagnosed are taken care of, but there continues to be additional medical advances so ultimately a cure for this horrible disease can happen in the foreseeable future. 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. Supporting Betty's Run is a great example of how we can all get involved and I am honoured to be part of it.”

**Donate, register or learn more at [bettysrun.ca](http://bettysrun.ca)**

# 2018 Edmonton WALK for ALS

## Meet the Ambassador - Adam Rombough

**Saturday June 9, 2018**  
**9 a.m. in William Hawrelak Park**

*Each year, the Edmonton WALK for ALS Committee selects an Ambassador to help show the public what it is like to live with the disease. The ALS Society of Alberta is thrilled to introduce Adam Rombough as the 2018 Edmonton WALK for ALS Ambassador.*



“My name is Adam Rombough and I am honoured to be the 2018 Edmonton WALK for ALS Ambassador. I have always approached life with passion and determination no matter what challenges I am faced with. In October of 2016 I was out for lunch with a client who asked me how long I have been waiting and how many drinks I had already had, because my speech was slurred. The answer was zero; this was one of the many symptoms that I had been experiencing. When I asked my family doctor he did not seem concerned, he brushed me off. After months of pursuing answers from other doctors, in February of 2017 at 32 years old I was diagnosed with ALS, a disease that is always fatal and has no cure. Because of these facts I chose to accept my diagnosis, rather than sitting around feeling sorry for myself. I embraced opportunities that were being presented to me. Within one week I had retired from my

career, and then I started living my life the way I wanted to. I began by traveling and started working on a documentary about my life with ALS. I also spend a lot of time developing the relationships that I value the most, because I have realized that that is the most important thing in my life.

Even though I choose to look at the positive things in my life everyday there are countless obstacles that I must face: relocating, renovating a house to fit all of the needs of being in a wheelchair, scheduling endless medical appointments, and purchasing and finding the right equipment to best suit my ever-changing needs. All while losing my ability to speak and take care of myself. It has been overwhelming to say the least. Throughout my journey I have realized we are not lacking loving and caring professionals who are willing to do what it takes to make my life easier and more comfortable. What we are lacking is funding and research which is why I am humbly asking you to get on board with supporting the ALS Society of Alberta.

The work that they do and the research that they fund has allowed me to focus on living my life to the fullest. I like to believe that I am not slowly dying, but I am quickly living”.

**Donate, register or learn more at [walkforals.ca](http://walkforals.ca)**





### EDMONTON WALK FOR ALS KICK-OFF BRUNCH

It was an incredible morning at the Edmonton WALK for ALS Kick-off Brunch on March 17. Over 85 people came together to get their fundraising started and to meet this year's Ambassador, Adam Rombough. Guests enjoyed a delicious brunch, several inspiring speeches, and took part in some friendly-competition with the ALS Society of Alberta themed Jeopardy game! If you would like any of the information that was shared through the game, contact Lisa@alsab.ca! Thank you to everyone who attended the brunch to celebrate another year of ALS fundraising success.

## Upcoming: Annual General Meeting

The ALS Society of Alberta  
7874 10 Street NE  
Calgary, Alberta, Canada T2E 8W1

**May 29, 2018– 6:00 to 7:00 p.m.**

Please R.S.V.P. by May 22, 2018 to Kim Rayner at Kim@alsab.ca or by calling the ALS Society of Alberta office at (403) 228-3857. Seating is limited.



### EDMONTON WALK FOR ALS PUB NIGHT

This year's Edmonton WALK Pub Party took place on April 7 at Brewsters Century Park. Over 50 people were in attendance to celebrate the exciting start of the 2018 WALK Season. The ALS Society was thrilled to have this year's Edmonton WALK Ambassador, Adam Rombough, in attendance. Over \$2,000 was raised through this year's ticket sales, silent auction and raffle. A huge thank you to the Edmonton WALK for ALS planning committee for volunteering your time to plan and attend this heartfelt community event!

## Community Events

### ▼ Bowling for ALS

The Drayton Valley WALK for ALS Committee organized a bowling night for ALS on March 10 at Thunder Alley. Over 115 people joined in to raise funds for the ALS Society of Alberta, with \$1,711 raised! Thank you to Nicole Tymchak, Melanie Pruden and Marcie Pruden for all of your hard work. This year marks the launch of the WALK for ALS in Drayton Valley. Join us at West Valley Lion's Park on Saturday June 16 at 10 a.m. for this incredible, grassroots event.



### ▼ Wild Rose Brewery Charity Pint

Over the month of February, the Wild Rose Brewery donated 25 cents for every “patron’s pint” sold. Thank you to everyone who visited the brewery to contribute to the ALS cause, and to the team at Wild Rose for selecting us as their February charity of choice!



### ▲ An Evening with Wayne Thomas

Friends and family of 2018 Betty’s Run for ALS Ambassador, Wayne Thomas, gathered on Jan. 25 to raise funds and awareness about ALS. Wayne generously donated \$1,000 of funds raised at the event to the ALS Society of Alberta. Thank you to everyone who participated!

### ▼ 9th Annual Darby Chrest Memorial Bowling Tournament

The ninth annual Darby Chrest Memorial Bowling Tournament took place at Heritage Lanes in Red Deer on January 1. This annual fundraiser is a consistent success and raises a great deal of awareness about ALS in the Red Deer Area. Thank you to everyone who attended and to all who volunteer their time to make this event happen. An incredible \$4,000 was raised this year, which will make a significant impact in the ALS community.



### ◀ The Purple Shirt Party

Saturday, April 14 marked the first annual “Karen’s Purple Shirt Party”. After losing wife and mother, Karen Wagenaar, to ALS in 2017, Rick and his four sons brought their family and friends together to pay tribute to Karen and her journey with ALS. Rick and his family consistently mentioned how they needed to do something special in honour of Karen, and continue her legacy through annual fundraising and support of the ALS Society of Alberta. Now, they are “overwhelmed by the support in their community” and managed to raise nearly \$25,000 for the ALS Society!



## ▼ Songs for Ken

April 12 and 13 marked another incredible Songs for Ken event in Fort Macleod and Calgary. Thank you to John Wort Hannam for all of your hard work in coordinating this fundraiser in honour of your friend, Ken Rouleau. A big thank you to The Polyjesters, Maria Dunn, Brooke Wylie, John Rutherford, Mike Stack and Annie Froese for your participation in such an inspiring event! The awareness and funds raised through Songs for Ken is truly remarkable.



## Upcoming Events

### 2018 QUONSET DAYS

VISIT [QUONSETDAYS.COM](http://QUONSETDAYS.COM) FOR MORE INFORMATION

## Upcoming WALKs for ALS

**Cold Lake - June 2**

Lakeland Lutheran Church

**Grande Prairie - June 9**

Muskosepi Park

**Red Deer - June 16**

Kiwanis Picnic Park

**Camrose - June 24**

Mirror Lake Park

**Edmonton - June 9**

William Hawrelak Park

**Fort McMurray - June 10**

Birchwood Trails

**Drayton Valley - June 16**

Birchwood Trails

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

### Team Danny ALS Walk Barbecue



Join us for our fundraiser! All proceeds to ALS walk on June 9th

Tickets \$10.00 includes a burger and pasta salad served from 5:00-7:00

Social / Meat Draw to follow  
\$5 Drinks

June 1, 2018 5:00-7:00  
Morinville Fish & Game Clubhouse

Contact Audrey 780-886-6579 or  
Danny 780-975-4777 for tickets



### DANNY GETZLAF COMMUNITY SPIRIT - WALK FOR ALS FUNDRAISERS

FRIDAY JUNE 1 - TEAM DANNY ALS WALK BBQ

TICKETS \$10 - INCLUDES BURGER AND SALAD  
5 - 7 P.M. | MORINVILLE FISH AND GAME CLUBHOUSE

SATURDAY JUNE 2

RAFFLE DRAW AND FUNDRAISER

1 - 7 P.M. | COACH'S CORNER, MORINVILLE

## RESEARCH UPDATE



The ALS Society of Alberta was thrilled to attend the 2018 national ALS research forum in Toronto from April 28-30. The progress that the research community has made is truly remarkable, with some groundbreaking research taking place in Alberta. The Society is proud to be the largest per-capita donor to the national research program and is looking forward to the continued momentum of ALS research. To learn more, visit [alsab.ca/research](http://alsab.ca/research).

## Bringing Edaravone to Canada

Mitsubishi Tanabe Pharma America (MT Pharma) has applied to Health Canada to bring edaravone to Canada following the Food and Drug Administration's approval of Radicava last year in the United States. For the first time in nearly 20 years the Canadian ALS community is now facing the possibility of a second treatment being approved by Health Canada. Now that MT Pharma's submission has been accepted for review, the next steps in the process include:

- Health Canada review of the drug which, if approved, will receive a Notice of Compliance (NOC). A NOC from Health Canada would give MT Pharma the green light to market the drug in Canada.
- Common Drug Review (CDR), which is administered by the Canadian Agency for Drugs and Technologies in Health (CADTH). The Common Drug Review results in reimbursement recommendations for public drug plans.
- Evaluation by the Patented Medicine Prices Review Board (PMPRB) to set the drug price.

The ALS Societies across Canada are pleased to see a Health Canada priority review, which would shorten the approval timelines to a target of 180 days. It is hopeful that the Common Drug Review and provincial reimbursement decisions will happen in a streamlined fashion to shorten the timelines between when the drug is approved and reimbursement decisions are made.

ALS Societies across the country will continue to voice the need for equal access to treatments for all Canadian families living with ALS to allow for timely, affordable access once approval is given.

# 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 AND KENNEDY'S GROUP

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

## YOUTH GROUP

For youth who have a parent or relative who has been affected by ALS.

## Calgary

### ALS Support Group

Dates: May 5, June 2  
Time: 1:30 - 3:30 p.m.  
Place: ALS Society Calgary Office  
Contact: 403-620-1358 | Leslie@alsab.ca

### ALS Family & Spousal Support Group

Dates: May 28, June 25  
Time: 1 - 3 p.m.  
Place: Quarry Park Library, Room #2  
108 Quarry Park Road SE  
Contact: 403-815-1567 | Rob@alsab.ca

### Staying in Touch

Dates: June 4, Aug. 13  
Time: 6:30 - 8:30 p.m.  
Place: ALS Society Calgary Office  
Contact: 403-815-1567 | Rob@alsab.ca

### PLS & Kennedy's Support Group

Dates: May 28, June 25, July 30  
Time: 1 - 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: May 15, June 19, July 17  
Time: 1:30 - 3 p.m.  
Place: ALS Society Edmonton Office  
Contact: 780-487-0754 | SocietyNorth@alsab.ca

### ALS Family & Spousal Support Group

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

### PLS & Kennedy's Group

Dates: May 18, June 15  
Time: 2 p.m. - 3:30 p.m.  
Place: ALS Society Edmonton Office  
Contact: 780-487-0754 | SocietyNorth@alsab.ca

### Staying in Touch

Dates: May 18, July 20  
Time: 11:30 a.m. - 1 p.m.  
Place: ALS Society Edmonton Office  
Contact: 780-487-0754 | SocietyNorth@alsab.ca

## Lloydminster

### ALS Coffee Group

Dates: TBA  
Time: 1 p.m.  
Place: Atrium Centre, Basement  
5010 49 Street, Lloydminster  
Contact: 780-487-0754 | SocietyNorth@alsab.ca

## St. Albert

### ALS and PLS Group

Dates: May 4, June 1, July 6  
Time: 2 - 3:30 p.m.  
Place: Servus Credit Union Place  
Morinville Room  
Contact: 780-487-0754 | SocietyNorth@alsab.ca

## Lethbridge

### ALS Support Group

Dates: May 25, June 29  
Time: 2 - 3:30 p.m.  
Place: Nord-Bridge Seniors Centre  
Contact: 403-620-1358 | Leslie@alsab.ca

### ALS Support Group

Dates: May 29  
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

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## 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.*