

Prairie to Peak

A PUBLICATION OF THE ALS SOCIETY OF ALBERTA

APRIL 2017



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Calgary Flames
“Better Halves”

Frida Engstrom with
the winner of Mikael
Backlund’s bucket!



GO FLAMES GO!

CALGARY FLAMES HOST ALS ICE BUCKET RAFFLE



The Calgary Flames “Better Halves” generously organized an ALS Ice Bucket Raffle in support of the ALS Society of Alberta. Tickets were sold at the Dec. 15 game versus the Winnipeg Jets.

Each player donated a signed piece of memorabilia stuffed inside of a signed ALS Ice Bucket! A whopping \$5,000 was raised through this event. Thank you so much to Mikael Backlund and Frida Engstrom for your ongoing and unwavering support of the ALS Society of Alberta!



Mikael Backlund generously donates tickets to our families each month, and hosts us at a Calgary Flames Game.

Since 2015, Mikael and Frida have hosted more than 35 families at these games. This experience creates lasting memories for our families and we are so grateful for Mikael and Frida's support!





WALK FOR ALS KICK-OFF BRUNCH

What a fantastic day at this year's Edmonton WALK for ALS Kick-off Brunch! Speakers included Board Member Cathy Martin, Jody Round from the WALK Committee, WALK Ambassador Fred Gillis, and the winner of the 2016 Team Challenge, Cathy Tuckwell. The afternoon finished off with an ALS Society of Alberta themed game Family Feud! Thank you to all who attended the brunch, and to James H. Brown for your consistent dedication as a sponsor of the Kick-off Brunch and the Edmonton WALK. We can't wait to see you all on June 10 in William Hawrelak Park for the 17th Annual Edmonton WALK for ALS!

Upcoming: Annual General Meeting

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

May 31, 2017 – 6:00 to 7:00 p.m.

Please R.S.V.P. by May 24, 2017 to Kim Rayner at Kim@alsab.ca or by calling the ALS Society of Alberta office at (403) 228-3857. Seating is limited.



WALK FOR ALS PUB PARTY

This year's Edmonton WALK Pub Party took place on April 7 at On the Rocks. Over 100 people were in attendance to celebrate the exciting start of the 2017 WALK Season. The ALS Society was thrilled to have this year's Edmonton WALK Ambassador, Fred Gillis, in attendance. Over \$2,500 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!



JOIN US IN CELEBRATING ALS AWARENESS MONTH

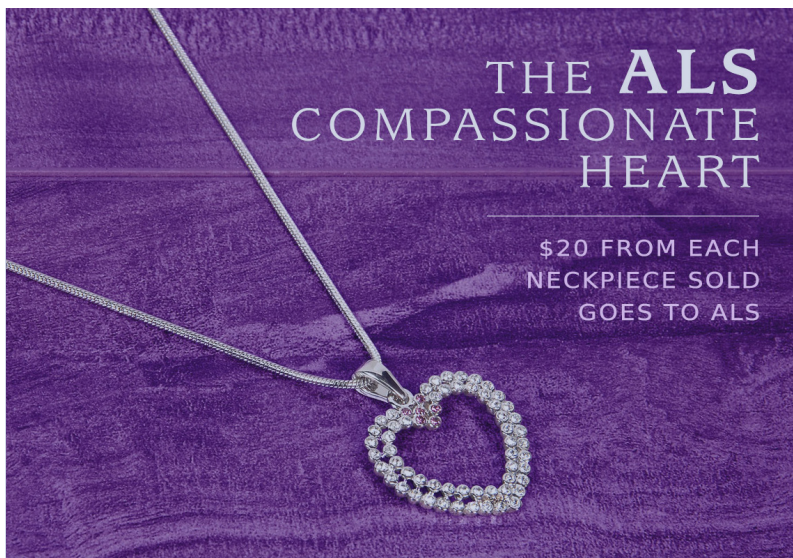
June marks ALS Awareness Month across the country. The ALS Society of Alberta would like you to join us during the month of June to celebrate the lives of those affected by ALS, and channel hope for a future without the disease. Towns and cities across the province have proclaimed June as ALS Awareness Month, and city council members will be attending the WALK for ALS in each hosting town. Sixty per cent of the funds raised at Betty's Run for ALS and the WALK for ALS remain in Alberta for client support services, and the remaining 40 per cent are invested into some of the most promising ALS research in Canada. To learn more about how you can honour ALS Awareness Month, contact alscommunications@alsab.ca.

Host your own
community event



Attend **Betty's Run** or the
WALK for ALS in your town

Visit Edmonton's **High Level Bridge** on **June 10** or the **Calgary Tower** on **June 11** as they light purple



The Fifth Avenue Collection is donating \$20 to the ALS Society for each ALS Compassionate Heart necklace purchased in Alberta. The ALS Compassionate Heart is a symbol of caring and support for people affected by ALS, the client, family, friends, physicians and caregivers. The ALS Compassionate Heart features 61 Swarovski Crystals each individually encased in a bezel setting. The pendant and the chain are finished in a rich Rhodium Finish. The chain is 20" and adjusts to 22". It is nickel, lead and cadmium free.

Please contact Lisa@alsab.ca or visit www.alsab.ca to purchase. Cost is \$59.99 and includes tax and shipping.

COMMUNITY EVENTS

▼ SONGS FOR KEN

To say the Society had an amazing weekend at Songs for Ken would be an understatement. This two-day concert raised a tremendous amount of funding and awareness in both Calgary and Fort Macleod, and brought the community together for a night of music and memories. Our sincerest gratitude to Brooke Wylie, The Polyjesters, Tanner James, The Sadler Brown Band, Oscar Lopez, Maureen Chambers, Randall Wiebe and the amazing organizer, John Wort Hannam. We could not be more grateful for the support within the Alberta music community. This was the third annual Songs for Ken event, which began in honour of John Wort Hannam's childhood friend, Ken Rouleau, who lived with ALS.



▼ TOUR DE FORCE

The Association for German Education in Calgary generously invited the ALS Society of Alberta to its January film screening of Tour de Force. The film chronicles a man living with ALS and his journey through Europe on bicycle, with his friends and family by his side. Thank you to the German Association for allowing the Society to attend and share its mission with the Calgary German community.



▲ GO OILERS!

Thank you to the Edmonton Oilers Community Foundation for providing one of our families with deluxe Oil Kings tickets at Rogers Place! Pictured in the photos are Helen Banks, her husband Jim, son-in-law Ryan and granddaughter Eilidh!



▲ CANMORE EAGLES

The Canmore Eagles broke a record in their weekday 50/50 jackpot by raising \$1,345.00, with proceeds of \$672.50 being donated to the ALS Society of Alberta. Thank you to the Canmore Eagles for all of your support and the awareness you bring to the ALS cause. It was a lovely tribute to former Eagles Board Member, Leslie Vanderzwet.



▼ DELBURNE BOTTLE DRIVE

A group of incredible fundraisers at Delburne Centralized School raised nearly \$1,000 for the ALS Society of Alberta through a community bottle drive. They also graciously invited the Society to their school assembly to raise further awareness about ALS in Delburne, and handed out purple bracelets across the town. A huge thank you to Hailey, Shianna, Keegan, Zach and Austin for giving back to the ALS community and honouring your loved ones through such an incredible fundraiser. It is supporters like you that help to make each day the best possible day for people living with and affected by ALS!

▲ SCENTSY FOR ALS

Eren Wiebe generously donated her Scentsy commission through an ALS online party. Her father has been living with ALS for 12 years, and she thought it was important to raise awareness within the Scentsy community. Eren raised an incredible \$430 during a two-week period, and the Society is so grateful for the funding and awareness she has brought to the cause.



▼ BOB ROCK INVITATIONAL

The Bob Rock Invitational Golf Tournament and Memorial Evening took place on Saturday, Jan. 21 in Mesa, Arizona! There was an exceptional turnout, with over \$3,000 raised for the ALS Society of Alberta. The event poster with Bob Rock's photograph raised \$1,000 through the live auction! Thank you to all event organizers, volunteers, donors and supporters!

▲ DUELLING PIANOS

It was an amazing night at the Duelling Pianos for ALS in Grande Prairie! Over \$9,000 was raised to support those living with and affected by ALS in Alberta. Thank you to The Dunes Golf & Winter Club and Mandy Van Dresar for all of your hard work in organizing this event!



UPCOMING EVENTS

SAVE THE DATE JULY 13.17

Second Annual **Bustin' Out ALS**

To donate an item to the silent auction, contact Lisa@alsab.ca

2017 WALK FOR ALS

Camrose (June 24, 2017)

Mirror Lake Park (Bill Fowler Centre)
Registration: 10:30 a.m.
Kick-off: 11 a.m.

Cold Lake (June 3, 2017)

Lakeland Lutheran Church
Registration: 10 a.m.
Kick-off: 11 a.m.

Edmonton (June 10, 2017)

William Hawrelak Park
Registration: 9 a.m.
Kick-off: 10 a.m.

Fort McMurray (July 16, 2017)

Birchwood Trails
Registration: 9 a.m.
Kick-off: 10 a.m.

Grande Prairie (June 10, 2017)

Muskoseepi Park
Registration: 9:30 a.m.
Kick-off: 10 a.m.

Hinton (Sept. 10, 2017)

Green Square
Registration: 9 a.m.
Kick-off: 10 a.m.

Lethbridge (Sept. 9, 2017)

Henderson Horseshoe Area
Registration: 10 a.m.
Kick-off: 11 a.m.

Peace District (TBA)

Riverfront Park
Registration: TBA
Kick-off: TBA

Red Deer (June 17, 2017)

Kiwanis Picnic Park
Registration: 9 a.m.
Kick-off: 10 a.m.

Valley Ridge (April 29, 2017)

Registration: TBA
Kick-off: TBA



Visit www.walkforals.ca to donate or register.

The ALS Society of Alberta
21st Annual Betty's Run for ALS
Sunday, June 11, 2017
9 a.m.
North Glenmore Park
bettysrun.ca

ALS PAINT NITE
June 4 | 1 p.m. | Heritage Lanes, Red Deer
Visit our website for more information



JODY PFEIFER

2017 BETTY'S RUN FOR ALS AMBASSADOR

"Hans Christian Andersen said, "Just living is not enough. One must have sunshine, freedom and a little flower." This little quote struck me as being so special and meaningful 15 years ago when I first discovered it. Going through papers and getting organized a month ago, it was rediscovered and this little saying took on a whole new special meaning to me.

My name is Jody Pfeifer. On August 3, 2016, I was diagnosed with ALS. Someone asked me, "Why you?" I responded "Why not me? This disease does not discriminate. If not me then someone else would be getting the diagnosis. It just as easily could have been you. The selection is purely random." Now I am the face of ALS.

I have lived a full life of fantastic adventures and memories. Having grown up in Vancouver, I was active for most of my life playing team sports, racquet sports, on track teams, jogging and doing lots of skiing. Right out of high school I

worked for a brokerage firm for ten years. When the firm was taken over in 1989, I moved to Calgary and never looked back. Little did I know I was about to experience the biggest adventure of my life! My son Ryan was born in 1992 and as a single parent still working in the brokerage business, I bought my first house in 1995. The purchase of that house ended up being the best trade I ever made! I still own that little house to this day and my son is living in it at the age of 24. My two greatest accomplishments have become one!

Although the majority of my family lives west of the Rockies, I have tons of "family" in Calgary. The people I've met and friends I have made over the years are considered family. These incredible people have shared their lives and homes with my son and I. They've been generous with their love and selfless with their caring and time. I love everyone in "my family" very much and it is this group of people who are now a part of my latest journey.

Having been fiercely independent my whole life, I've gone from being able

to do/fix anything (tools included) to not being able to use an elastic or open a Ziploc bag. With each ongoing muscle twitch I think of the paralyzing, insidious dark journey this disease is taking through my body and wonder about what I won't be able to do tomorrow? We all have to go sometime; it's just a matter of when and how...

For the most part I'm staying positive, thankful for having so many incredible people in my life and having the gift of time to tie up loose ends. I've discovered that the littlest things have so much more meaning now - a little flower, dogs playing, fresh air and the warmth of the sun. One must have freedom, yes, but one must also have the freedom of their bodies to move to continue to take you on more adventures...

Just being alive in your life isn't enough. LIVE your life because none of us knows if someday all you will have left is the memories of a life well lived..."

- Jody

RESEARCH UPDATE



**CANADA JOINS INTERNATIONAL
ALS RESEARCH COLLABORATION
PROJECT MINE**

Genetic study to answer questions about why
some people develop ALS while others do not,
in order to **better target the disease**

www.als.ca/projectmine

Canada has become the 17th country to join an international research partnership that is working to determine why some people develop ALS while others do not. Numerous Canadian ALS researchers are stepping up in a cross-country collaboration that is among the first of its kind in the country.

The provincial ALS Societies across the country are spearheading efforts for the Canadian component of Project MinE, a multi-national initiative that gained momentum following the ALS Ice Bucket Challenge. Project MinE will map the full DNA profiles of 15,000 people with ALS and 7,500 control subjects, establishing a global resource of human data that will enable scientists worldwide to better target the disease by understanding the genetic signature that leads someone to develop ALS.

By accumulating such a large amount of data that no one country could achieve alone, it is expected that Project MinE could identify new genetic causes of the disease. The discoveries gained through Project MinE have the potential to significantly accelerate the ability to advance treatment possibilities that could slow down or even stop ALS. Canada's goal is to contribute up to 1,000 DNA profiles to the international effort.

Research expertise for Canada's Project MinE effort is being provided by four of the country's leading ALS geneticists in Québec City, Vancouver, Toronto and Montréal:

- Dr. Nicolas Dupré, Neurologist; Assistant Professor, Faculty of Medicine, Université Laval; Clinician-Scientist, Axe Neurosciences, CHU de Québec - Université Laval, Québec City
- Dr. Ian Mackenzie, Professor at the University of British Columbia; Staff Neuropathologist at Vancouver Coastal Health, and a Consultant Neuropathologist, BC Cancer Agency, Vancouver
- Dr. Ekaterina Rogaeva, Chair in Research on Dementia with Lewy Bodies at Tanz Centre for Research in Neurodegenerative Disease, and Professor, Department of Neurology, Faculty of Medicine, University of Toronto, Department of Medicine
- Dr. Guy Rouleau, Director of the Montréal Neurological Institute and Hospital and Department of Neurology and Neurosurgery, McGill University, Montréal

Each of the participating researchers has led or been part of international consortia that have resulted in some of the most important genetic discoveries in the field. They also represent a geographical balance that would provide a collaborative set of Canadian samples representative of ALS cases across the country. Project MinE represents their first-ever cross-country collaboration.

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.

NEUROMUSCULAR DISORDER SUPPORT 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 6, June 3
Time: 1:30 p.m. - 3:30 p.m.
Place: ALS Society Calgary Office
Contact: 403-714-8211 | Jane@alsab.ca

ALS Family & Spousal Support Group

Dates: April 18, May 25
Time: 6:30 p.m. - 8:30 p.m.
Place: 8211 Churchill Drive SW
Contact: 403-714-8211 | Jane@alsab.ca

Staying in Touch

Dates: June 5
Time: 6:30 p.m. - 8:30 p.m.
Place: ALS Society Provincial Office
Contact: 403-620-1358 | Leslie@alsab.ca

Neuromuscular Disorder Support Group

Dates: April 24, May 29, June 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: April 18, May 16, June 19
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: April 18, May 16, June 19
Time: 1:30 p.m. - 3 p.m.
Place: ALS Society Edmonton Office
Contact: 780-487-0754 | SocietyNorth@alsab.ca

Neuromuscular Disorder Support Group

Dates: April 21, May 19, June 16
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 19
Time: 11:30 a.m. - 1 p.m.
Place: ALS Society Edmonton Office
Contact: 780-487-0754 | SocietyNorth@alsab.ca

Youth Group

Dates: April 28, May 26, June 30
Time: 6 p.m. - 8 p.m.
Place: TBA
Contact: 780-487-0754 | SocietyNorth@alsab.ca

Leduc

ALS Support Group

Dates: April 20, May 18, June 15
Time: 2 p.m. - 4 p.m.
Place: Karunia House
Contact: 780-707-0381 | Brandee@alsab.ca

Lethbridge

ALS Support Group

Dates: Last Friday of the month
Contact: 587-583-3848 | Shayla@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.