# Prairie to Peak

A PUBLICATION OF THE ALS SOCIETY OF ALBERTA ISSUE 03  $\mid$  APRIL 2016







# MESSAGE FROM BOARD CHAIR

"As Chair of the Board for the ALS Society of Alberta, it is my pleasure to express our sincere appreciation for all the staff and volunteers who work tirelessly on Betty's Run, all the WALKS for ALS throughout the province and all the additional events inspired to support the Society annually. Without this support, the Society would not be able to continue with its mission of making each day the best possible day for people living with and affected by ALS. We value each and every one of you and look forward to experiencing all the wonderful events planned for 2016!

Sincerely,

### Jan Desrosiers

Chair, ALS Society of Alberta"

### **CALGARY OFFICE MOVE**

On March 17, the Calgary office officially moved into its new home at 7874 10 Street NE. It is so exciting to now have combined office and warehouse space, that can house all of the equipment that has been purchased due to the generous support of donors. Thank you to everyone who helped make this move possible. This new space will greatly help in making each day the best possible day for people living with and affected by ALS.





# **THANK YOU!**

A heartfelt thank you goes to Ken Germain, from the Rotary Club of Edmonton, who dropped off seven, brand new manual wheelchairs!! This is such a tremendous addition to the equipment loan program, and the ALS Society of Alberta is so grateful for the support!



In collaboration with health care professionals and medical equipment vendors, the ALS Society is able to support the rapidly changing needs of Albertans affected by ALS. Through the provincial loan program, the Society is able to assist people affected by ALS by lending power mobility devices, assistive communication devices, and other medical equipment. The equipment loan program is free of charge, to ensure support is available when needed. The Society covers the costs of delivery and pickup, and once the person no longer requires the equipment, it is cleaned and returned to the loan pool.

### **CALGARY**



### **EDMONTON**



"The Equipment Loan program has been able to grow each year due to the generous support of our donors. It has been our vision for many years to have our own warehouse capacity in both Northern & Southern Alberta to efficiently provide the equipment needed to make each day the best possible day for those affected by ALS. We are so proud of how far we have come and hope to continue building as time goes on. Thank you to everyone who has helped make the Equipment Loan Program such a success."

Jeremy Wotjkiw Manager, Equipment Loan Program ALS Society of Alberta

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# BETTY'S RUN FOR ALS - 20TH ANNIVERSARY!



The 20th Anniversary of Betty's Run for ALS is here! Betty's Run celebrates, promotes and channels hope for those affected with ALS, their families and their friends.

The story began in 1996, when Calgarian Betty Norman was diagnosed with ALS. Her year-long physical and emotional battle with this terrible disease inspired her friends and family to organize an annual fundraiser. Over the past 20 years, Betty's Run for ALS has grown steadily to become one of the largest ALS fundraisers in Canada.

To date, Betty's Run has raised more than \$6.5 million due to the generous support of donors and participants. Of funds raised, 60 per cent stay in Alberta to support those

currently living with ALS through equipment and client services. The remaining 40 per cent of funds support ongoing research into identifying the cause and cure for this devastating disease.

This year we are inviting our past 20 years of "Betty's Run family" back, along with new friends to continue inspiring care, hope and community, and to celebrate our 20th anniversary milestone! Visit www.bettysrun.ca to register.

Sunday, June 12, North Glenmore Park 9 a.m.



Each year, the Betty's Run for ALS Committee selects an Ambassador, who is someone that is currently living with ALS. The Ambassador courageously shares their story with the public to show what it is like to live with the disease. The ALS Society of Alberta is so proud to introduce Erin Serack as the 2016 Betty's Run for ALS Ambassador.

"I can still vividly recall a question from a job interview I attended when I was about 19 years old; "Do you consider yourself to be a lucky person?" I remember pausing briefly before replying "No, I don't." The interviewer then asked me "What makes you say that?" to which my response was "Well, I've never won any contests or the lottery...I'm really not lucky at all!" The interviewer then spoke again, "We don't believe you need to win the lottery to be considered lucky. We believe if you've had a good upbringing, a loving family, a roof over your head, food on the table, access to education, and freedom to pursue the things you want in life, you are lucky." It was a moment of awakening for my ego-centered 19 year old brain, and I've reflected on those words almost every day of my life since.

The truth is, I was very lucky, and have continued to be extremely fortunate throughout my life. One might expect that when I received my diagnosis of ALS that I may have felt as though my run of good luck had ended, and that I would be angry or bitter. But I soon realized that what I did have was right here, right now. I had a choice to dwell in what might be, or embrace what is. I chose the latter; to embrace my diagnosis as a blessing in my life. In doing so, in the past year I have met some of the most amazing people with incredible spirit, and have been able to experience the good in people; their caring, their love, their support. Perhaps it has been there all along, and I just wasn't open to it. What a blessing to have been gifted another awakening; I again view the world from a different perspective. And I am grateful. Every single day."

#### To read the rest of Erin's story, visit www.bettysrun.ca



# SONGS FOR KEN

On Feb. 12 and 13, John Wort Hannam hosted the second annual Songs for Ken fundraiser in support of the ALS Society of Alberta. The event is held in honour of John's closest childhood and adult friend, Ken Rouleau, who lived with ALS. When John first learned of his friend's diagnosis in 2011, he immediately began organizing fundraisers to help with the financial burden of the disease.

This year's event was a huge success, with a concert held in both Calgary and Fort MacLeod. The Calgary show featured John Wort Hannam, Karla Adolphe, Maria Dunn, Amy Bishop, John Rutherford, The Polyjesters and visual artist Randall Wiebe, who awed the crowd with live portraits he created during the show. Calgary's Southwood United Church was completely sold out, as families gathered to celebrate the lives of their loved ones, and pay tribute to the life of Ken Rouleau.

The Fort Macleod show added Dave McCann to its line-up, a blues artist from Calgary, and took place at the Empress Theatre. Each artist

played short, 15 minute sets to add variety to the show. Funds raised at Songs for Ken will be allocated toward essential client services in the province.

to the ALS community, and is filled with inspiration and the celebration of life. Most importantly, the event is held in honour of John's close friend Ken. The concert not only raised much needed funds to support people in Alberta affected by ALS, but also raised awareness about this

horrific disease. We cannot thank John enough for his dedication and support." said ALS Society of Alberta Executive Director, Karen Caughey.

John plans to continue the fundraiser on an annual basis. He hopes to continue raising funds for ALS, and to have the opportunity once a year to gather the ALS community, and remember his good friend Ken.

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### **ALS SOCIETY EVENTS**



The WALK for ALS is one of of the signature events hosted by the ALS Society of Alberta. In 2015, there were 12 WALKs for ALS across the province, plus Betty's Run for ALS in Calgary. The total amount raised at these events was over \$1,007,030! Each WALK is organized by a hardworking team of volunteers, with support from the ALS Society of Alberta. This year, there will be 13 WALKs for ALS taking place across Alberta. Visit www.WALKforALS.ca to register.

### Barrhead (May 21, 2016)

Barrhead Agrena Registration: 9:30 a.m. Kick-off: 10 a.m.

### Camrose (June 25, 2016)

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

### Cold Lake (June 4, 2016)

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

### DeBolt (TBA)

DeBolt Sports Field Registration: TBA Kick-off: TBA

### Edmonton (June 11, 2016)

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

### Fort McMurray (July 17, 2016)

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

### Grande Prairie (June 25, 2016)

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

### Hinton (June 19, 2016)

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

### Lethbridge (Sept. 10, 2016)

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 18, 2016)

Great Chief Park Registration: 9 a.m. Kick-off: 10 a.m.

### Spruce Grove (Sept. 10, 2016)

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

### Vegreville (TBA)

Elks Kinsmen Park Registration: TBA Kick-off: TBA





### WALK FOR ALS LUNCHEON

A heartfelt thank you to everyone who gathered for the 2016 Edmonton WALK for ALS kick-off brunch on March 5. It was such an uplifting day, with speeches from WALK Coordinator, Alanna Supersad, Provincial WALK Sponsor, James H. Brown, **2016 WALK Ambassador, John Orfino** and long-term member of the ALS Society Board, Cathy Martin! A great time was had playing the Price is Right, hosted by Client Services Coordinator, Brandee Fossen. A game of "Name the Hub-Scrub was also played, to name the Society's sanitising machine! After many different votes, a combination of two ideas was decided upon: Al's Autobody - Degerminator! Thank you to everyone who helped make this event such a success.



### WALK FOR ALS PUB PARTY

Ambassador John Orfino and Family

This year's Edmonton WALK Pub Party took place on March 12 at Devaney's Irish Pub. Over 130 people were in attendance, including Ryan King and Grant Shaw of the Edmonton Eskimos - who graciously donated a signed CFL game-used football for the silent auction! Devaney's also donated a pair of tickets to the March 14 Oilers game vs the Predators. There was a 50/50, a prize draw with assorted refreshments and tools, and tickets were sold for the upcoming afghan and quilt raffle on WALK day! Combined, the 2016 Luncheon and Pub Party raised over \$2,800! Thank you to everyone who attended, and to our WALK Ambassador, John Orfino, for giving such an amazing speech! It is always so exciting to start another WALK season, visit www.walkforals.ca to learn more!

# GO FLAMES GO

The Society is thrilled to have continued its partnership with Mikael Backlund and the Calgary Flames

Mikael has been hosting clients and families at home games each month, and has been an amazing advocate and supporter for ALS in the community

A big thank you to Mikael and his girlfriend, Frida, for making memories with the ALS community and for raising awareness about this disease.







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### **CAMP-OUT FOR ALS**

The Camp-out for ALS is an annual event held by the Lloydminster Fire Department. Each year, these dedicated fundraisers camp-out on the roof of the firehall until they reach their fundraising goal. This year, the event took place from Nov. 27-29, and they raised over \$29,000! This was a record-breaking achievement for these fundraisers, and fortunately, this year they did not have to brave a blizzard like they did in 2014! A heartfelt thank you to everyone who participates in this annual event. Camp-out for ALS raises a great deal of awareness in the Lloydminster area, and continues to be an incredibly successful fundraiser!



### MRU COUGARS ALS FUNDRAISER

The Mount Royal University Women's Hockey team dedicated its game on Feb. 5 to the ALS community. The ladies wore original jerseys complete with the purple ALS ribbon and the phrase "no one fights alone". The team chose to fundraise for ALS in honour of four individuals who have been affected by ALS: Kyle Ruppe, former Cougar's men's hockey player, Barb Sorensen, the grandmother of current Cougar, Mairi Sorensen, Mike Sands, the father of former Cougars women's hockey player Madison Sands, and Virginia Winkler, aunt of former Cougar's coach, Carla MacLeod. Thank you to Mount Royal University for hosting this incredibly hopeful and heartfelt event.



### KIDS HELPING KIDS

Ruby Padbury, dedicated fundraiser, and granddaughter of Client Services Coordinator Jane Rivest, hosted her very own ALS fundraiser in support of the Support for Champions program. Ruby sold hot chocolate and coffee to her friends and neighbours to help raise awareness about ALS in her community. This wasn't the first time Ruby organized her own fundraiser. She also held a lemonade fundraiser in the summer of 2015, complete with song and dance to help draw attention to her fundraising station. Thank you so much for all that you do, Ruby! Your fundraising is so inspiring, and truly makes a difference in the lives of children who are affected by ALS!

# **UPCOMING EVENTS**







# ANNUAL GENERAL MEETING

May 19, 2016, 6 p.m.
ALS Society of Alberta Calgary Office
7874 10 Street NE

RSVP to Diane Kirby Diane@alsab.ca

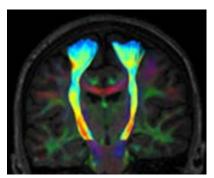
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### ALS RESEARCH IN ALBERTA

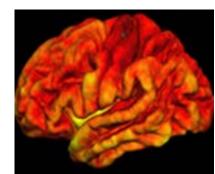
### Magnetic Resonance Imaging Study

Magnetic resonance imaging (MRI) is a tool that can be used to examine the structure, chemistry, wiring and function of the brain using advanced high powered MRI scanners and newly developed techniques to study changes in the brain that are not visible using standard MRI machines. The aim of this MRI study is to improve researchers' understanding of the symptoms and progression of ALS/MND, as well as to aid in earlier diagnosis of ALS and the evaluation of new treatments. MRI is a safe technique that does not use harmful radiation.

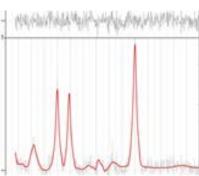
Recruitment is now underway for patients with ALS and other motor neuron diseases as well as healthy individuals to participate in a longitudinal Canada-wide MRI study led by Dr. Sanjay Kalra that includes both the University of Alberta and the University of Calgary. Participants must be able to lie still inside an MRI machine for approximately 60 minutes, have no metallic objects in body, and be over the age of 40.



MRI image showing the brightly coloured "corticospinal tract", a bundle of fibers that carry information from the motor cortex to the motor neurons in the spinal cord.



A 3-dimensional image of the brain constructed from MRI data. The surface of the brain is colour-coded to indicate the thickness of the gray matter



The different peaks in this figure represent different chemicals that were measured from the motor cortex in the brain using advanced MRI techniques.

### **Brain Imaging Study**

MRI methods can reveal changes in the brain not visible using standard techniques. These advanced MRI methods are being developed as tests to evaluate new drugs faster, diagnose patients sooner, and improve the understanding of this complex disorder. Participation is possible at ALS centres in Edmonton and Calgary. Patients with ALS, as well as individuals without ALS over the age of 40 are eligible.

If you have any questions or would like to participate in one of the studies above, please contact als@ualberta.ca

### 2016 RESEARCH FORUM

### Calgary

Saturday May 14, 2016 1:30 p.m. - 3:30 p.m. South Health Campus, Auditorium B, Second Floor

Please join us for presentations by Dr. Lawrence Korngut, Director of the ALS and Motor Neuron Disease Clinic, and Dr. David Taylor, Director of Research with ALS Canada.

RSVP to Diane@alsab.ca

### Edmonton

Sunday May 15, 2016 1 p.m. - 3 p.m. Holiday Inn, Calgary Trail

Please join us for presentations by Dr. Sanjay Kalra, neurologist and ALS specialist at the University of Alberta, and Dr. David Taylor, Director of Research with ALS Canada.

RSVP to SocietyNorth@alsab.ca

### **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 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: April 23, June 25
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 14, May 26, June 16
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: April 4, June 6
Time: 6:30 p.m. - 8:30 p.m.
Place: ALS Society Provincial Office
Contact: 403-620-1358 | Leslie@alsab.ca

### Neuromuscular Support Group

Dates: April 25, May 30, June 27

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 19, May 17 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 19, May 17 Time: 1:30 p.m. - 3 p.m.

Place: ALS Society Edmonton Office

Contact: 780-487-0754 | SocietyNorth@alsab.ca

### Neuromuscular Support Group

Dates: May 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: May 20

Time: 11:30 a.m. - 1 p.m.

Place: ALS Society Edmonton Office

Contact: 780-487-0754 | SocietyNorth@alsab.ca

#### Youth Group

Dates: April 29, May 27 Time: 6 p.m. - 8 p.m.

Place: ALS Society Edmonton Office

Contact: 780-487-0754 | SocietyNorth@alsab.ca

### Leduc

### **ALS Support Group**

Dates: April 21, May 19
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

### **Red Deer**

ALS Support Group

Dates: Every other month
Time: 1 p.m. - 3 p.m.
Place: MS Society Office
105, 4807 50 Avenue

### ALS Family & Spousal Support Group

Date: Third Thursday of the month

Time: 1 p.m. - 3 p.m.
Place: Contact for details

Contact: 403-357-4791 | Carla@alsab.ca

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"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 BECOMING A MONTHLY DONOR

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	rm to the ALS Society those living with and		fice. Your gift will help us to make each day

PRIVACY STATEMENT: Your personal inforation will noy be traded, sold, or shared without knowledge or consent. For more information, please call the ALS Society of Alberta's Provincial Office.