

Prairie to Peak

A PUBLICATION OF THE ALS SOCIETY OF ALBERTA

DECEMBER 2018



IN THIS ISSUE

1. Giving Tuesday
2. Making It Possible
3. Appreciation Night
4. WALK for ALS
5. Community Events
6. Research Update
7. Support Groups
8. Ways of Giving





GIVING TUESDAY

November 27



Giving Tuesday

Most people know about Black Friday and Cyber Monday, but now Giving Tuesday has taken Canada by storm by encouraging a day of charitable giving. November 27 marked the 2018 Giving Tuesday, and the ALS Society of Alberta celebrated by raising funds for the Support for Champions program. This program allows children whose parents are affected by ALS to participate in childhood activities that may not be available to them due to the immense financial burden of ALS.

“

My son, Owen, received money for his basketball season this year from the Support for Champions program. His father has been living with ALS for the past five years. Owen loves playing basketball, skiing, biking, snowboarding and playing video games. When he is visiting his dad, he makes paper airplanes to hang in his room. He is a creative, active and loving seven-year-old and we thank the Support for Champions program for giving him the opportunity to play basketball this year.

Support for Champions Recipient



The need for this type of support is real and is currently not being met for some families in Alberta. Many families do not have the financial means and social network to be able to ensure that the children affected by ALS are able to engage in social activities, process their grief, enjoy childhood and look forward to a bright and promising future. For some families there is a struggle in balancing financial responsibilities and recreational activities, a struggle that the Support for Champions program aims to help. The Society received nearly \$8,000 this year in donations. These contributions will make a significant impact in the lives of children and youth affected by ALS, and the Society would like to thank each and every donor that pledged their support through Giving Tuesday!

Making It Possible

Another hockey season has begun, and Mikael Backlund has continued to host our families at the Calgary Flames Game! Thank you Mikael for making these memories with the ALS community!





Colleen Kovaluk & Peter Chan

Colleen Kovaluk dedicated her career to the health care field until she was diagnosed with ALS in 2015. Colleen along with her husband Peter, took on an unsurmountable task to advocate with the Provincial Government to amend the Local Authorities Pension Plan (LAPP) Regulation to include provisions consistent with those required under the Employment Pension Plans Act related to the unlocking of pension benefits due to considerably shortened life expectancy.



Colleen found champions that would help her weave her way through the complicated and sometimes frustrating maze. When one door closed, she opened another. Colleen was the voice behind the changes that needed to be made to accommodate plan members coping with a terminal illness who needed financial relief. Colleen met with LAPP officials, Alberta Government officials, United Nurses of Alberta, the ALS Society of Alberta and Finance Minister Joe Ceci.

Nineteen months later, Colleen was informed by Minister Joe Ceci that the amendment will be done. Colleen was able to access her pension benefits. This is truly an example of selfless dedication and how changes are possible in the face of adversity.

Appreciation Night

On November 8, the Alberta ALS community gathered to celebrate the incredible achievements of volunteers and staff in 2017. Celebrations occurred in both Calgary and Edmonton, and provincial awards were given to a number of the Society's volunteers and supporters. Thank you to everyone who joined us in recognizing these achievements.



Norman Pollock - Exceptional Volunteer Award
Jean Ramsey



Norman Pollock - Exceptional Volunteer Award
Jody Round



Exceptional Public Awareness Program Award
Danny Getzlaf



WALK for ALS Award
Drayton Valley



Proud Supporter
Allan Jones & Andrew Smith



Proud Supporter
Sean MacDonald

Appreciation Night



**WALK for ALS Award
Fort McMurray**



**Exceptional Fundraising Program Award (3rd Party
Event)
Jim Robinson – Big Drew’s Big Ride**



**Exceptional Fundraising Program Award (3rd Party
Event)
O’Connor Family– PJ Impact**



**Making Possibilities
Glen Jarbeau**



**Leader of Tomorrow Award
Payton Moro**



**Long-term Service
Cathy Martin - 15 years**

WALK for ALS



Lethbridge

The Lethbridge WALK for ALS raised \$35,000 on Saturday morning, and counting! Congratulations to top fundraiser Joyce Berg on your achievements, and thank you to the Thom family and friends for your continued support with the WALK! Thank you to all donors, participants and sponsors!



Hinton

It was an incredible morning at the 2019 Hinton WALK for ALS on Sunday, raising \$8,500 and counting! A huge thank you to our Hinton WALK Ambassador Helen Banks, WALK coordinators Deena Fuller & Sandi Rasmussen-Connolly and to all donors, participants and sponsors! Great work to all the teams that participated including Kickin' It for Kenny and Helens Heroes!

COMMUNITY EVENTS

▼ Big Drew's Big Ride

This year marked the fifth and final Big Drew's Big Ride in support of the ALS Society of Alberta. Event organizer, Jim Robinson, created this event with his best friend Drew, after Drew was diagnosed with ALS. Five years later, this event has raised over \$58,000 for ALS, has brought over 100 riders together of all ages that have clocked thousands of kilometers along the Legacy Trail. Thank you Jim, for your incredible dedication over the past five years. What a beautiful tribute to a beautiful friendship.



▼ CalFrac 150 Putt Fore Charity



Thank you Crescent Point Energy for supporting the ALS Society of Alberta through the CalFrac 150 Putt Fore Charity! An exceptional \$1,875 was raised!

▼ AOC Golf Tournament

Wow! We are completely blown away by the generosity from the golf tournament on Tuesday! \$4,800 was raised along with an additional \$450 that was graciously donated by the 50/50 winner, bringing the total to \$5,250!! Thank you to Jeff Goyer, Kelsey Smith and everyone on the AOC board committee for all your hard work and incredible support!



▼ Phi Delta Theta 24-hour Teeter Totter Marathon for ALS

The Phi Delta Theta Fraternity at the University of Alberta hosted the annual 24-hour teeter totter marathon for ALS in early October. This event has raised a great deal of awareness among the university community since its inception, and raised over \$6,000 this year! Thank you to Jack and the rest of the fraternity for your hard work!



A special thank you to Wendy Schilling and Frieda Vanherck for donating \$1,240 from their pickleball tournament. We are so grateful for your contribution to the Society!

◀ Pickleball Tournament

Shaw Birdies for Kids ▶

We were thrilled to be a part of the Shaw Charity Classic Birdies for Kids fundraiser this year! Donations made to our organization were be matched up to 50 per cent. All the funds went towards Support for Champions.



▼ Judy Schweitzer ALS Curl for ALS

The ninth annual Judy Schweitzer ALS Curl for a Cure took place on Saturday, November 10 in Red Deer! The event was another huge success, with an incredible prize draw and a great deal of awareness raised for the Society. Thank you to Carrie Mello, and all of her friends and family that help to make this event happen each year. Carrie began the Funspeil in honour of her mother, Judy, in 2010 and has been an exceptional support for the Society ever since!



Leigh Reed Art Show ▼

On October 6th, Leigh Reed held a private art show and sale displaying her work with a photo raffle with all proceeds going to the ALS Society. Leigh's art work included Canadian landscapes and photographs and posters. Thank you Leigh for your generosity.



Hike for ALS ▼

David Xiao believes that living with ALS means waking up and conquering mountains every day, so he choose to conquer his own mountains for ALS research. David took a 7 month leave from work to hike the Pacific Crest Trail (PCT), a 2,600 mile trail from the border of Mexico to Canada. This year, his co-worker Mike was disgnosed with ALS, which inspired him to undertake this meaningful adventure to support a cause he is passionate about. David asked people to pledge an amount per mile and donate the amount based on the miles he completed at the end of the summer. David completed the PCT trail in September 2018 and has raised over \$4,000 and counting! This has been a tremendous undertaking and we are so grateful!



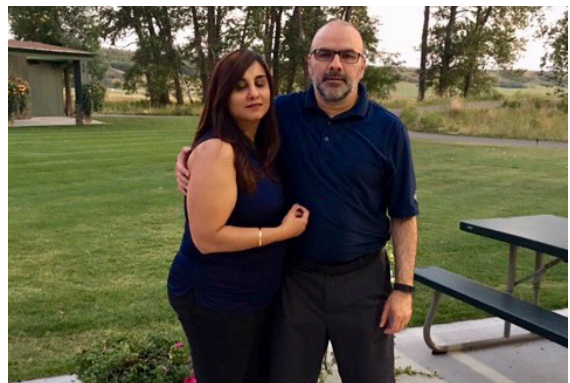
Thank you so much to Veronique Lepage on her work for the Tim Horton's Smile Cooking Campaign at the Calgary Airport. HMS Host Airports and SMSI Travel Centre raised \$2,692 during the week of Smile Cookie 2018!

Tim Horton's Smile Cookie Campaign ▲

I Golf 4 Gurdev ▼

Nivi and Ravinder Uppal hosted the first annual I Golf 4 Gurdev at the Cottonwood Golf & Country Club in Calgary. The tournament was held in honour of Ravinder's dad, Gurdev Singh Dhillon.

Gurdev was diagnosed with ALS in 2013 and after a courageous battle, passed away in 2015. Nivi and Ravinder generously dedicated the funds raised to the ALS Society of Alberta. It was a great day with support from friends, business partners and colleagues. What a wonderful dedication to Gurdev.





Family Screening of The Grinch

Nearly 100 people were in attendance on November 18 at a private screening of *The Grinch*. Thank you to Glen Jarbeau and family for creating such a warm and inviting atmosphere for families affected by ALS! Glen continues to provide a number of social opportunities for the ALS clients and their families.

Bouge's Buds

The Debogorski family in Yellowknife held their second annual Bouge's Buds fundraiser in honour of Andrew who is living with ALS. They graciously donated a percentage of proceeds to the ALS Society of Alberta! The Society is so grateful for all of the support and awareness that the Debogorski family continues to raise in the Yellowknife area, and wish them the sincerest of congratulations for such a successful fundraiser!

Lloydminster Fire Department ALS Rooftop Campout

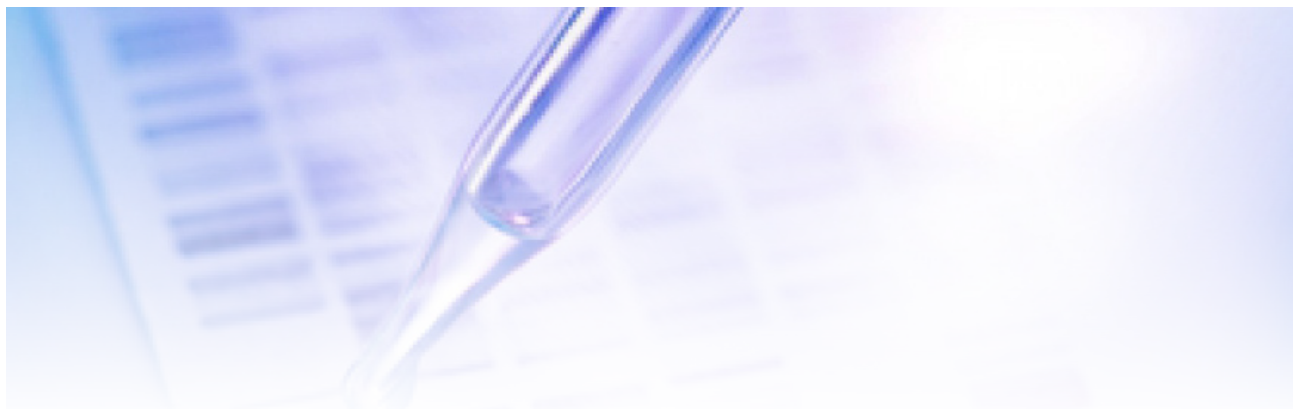


From November 23 – 25, the Lloydminster Fire Department camped on the roof of the fire hall in support of the ALS Society of Alberta. This year's event raised nearly \$24,000 for the Society, making it one of the largest community fundraisers in the province. Thank you to Deputy Chief Brad Martin, Fire Chief Jordan Newton and the rest of the fire department for the consistent support, and for the awareness raised in the Lloydminster area!

Moro Memorial Ride

The third annual Moro Memorial Ride took place at YYC Cycle on October 14. The studio graciously donates three classes to the ALS Society of Alberta, encouraging participants to donate and raise awareness about the cause. In memory of her mother, Payton Moro worked hard to organize a silent auction and fundraising website that raised over \$5,000 for the ALS Society of Alberta. Thank you to the spin instructors at YYC Cycle for your support, and to the Moro family for all that you do!





Research Update

The ALS Society of Alberta is proud to be one of the largest contributors to the ALS Canada Research Program. Thank you to our generous donors in Alberta.

The ALS Canada Research Program awards eight new project grants in the pursuit of new therapy targets **Health Canada has approved Radicava (edaravone), a second ALS treatment for Canadians**

The eight new research projects being funded include multiple studies using cutting-edge techniques, never before applied to ALS, further examination of newly discovered proteins that may be critical to understanding how ALS works in the body, the use of specialized models of ALS to better understand how the disease occurs, a new spin on targeting abnormal immune and inflammatory mechanisms to treat ALS, and development of a unique Canadian protocol to measure the value of therapies on quality of life alongside medical evaluation in clinical trials.

On October 4, Health Canada approved Radicava (edaravone) for the treatment of ALS. Health Canada's terminology for this approval is called a Notice of Compliance, or NOC. The approval follows a 180-day priority review of the drug. Approval from Health Canada means that Radicava (edaravone) can be marketed and sold in Canada. Other considerations, like the price of the drug and whether it will be covered through provincial drug plans, have not yet been determined and are separate steps in how drugs become approved and available to Canadians.

Research Forum in Calgary and Edmonton

Both our Calgary and Edmonton offices hosted Research Forums where ALS clients and families were welcomed to hear about the new research initiatives and updates from across the province and Canada. Dr. Korngut presented to the Calgary clients while Dr. Kalra updated the Edmonton and area clients. The well attended forum saw approximately 35 people in attendance at the Calgary office and 30 at the Edmonton office. It was a great opportunity for clients to ask questions and inquire about exciting research updates and news.





would like to
make you aware of:



What is CNDR?

The Canadian Neuromuscular Disease Registry (CNDR) is a Canada-wide registry of people diagnosed with a neuromuscular disease. It collects important medical information from patients across the country to improve the understanding of neuromuscular disease and accelerate the development of new therapies.

How does it work?

If you choose to register with the CNDR, your doctor will submit information collected at your regular visits. Your name and other identifying information are removed and stored separately to ensure your privacy and data security.

Why should I get involved?

- Help find a meaningful treatment for neuromuscular disease
- Learn how to participate in important research
- Receive information about clinical trials for new treatments

Who can participate?

Anyone with a neuromuscular disease is eligible. Enrollment is voluntary, Confidential, and free of charge.

How is the information used?

Medical data is pooled in a computer database with information obtained from other patients across Canada. This builds a picture of how people with neuromuscular diseases are affected over time, and enables development of new treatments. This knowledge can be used in many ways:

- To help understand the burden these diseases create and direct resources to where they are needed most
- To increase understanding of diseases
- To enable new research studies and clinical trials
- To improve clinical care and disease management
- To improve the chances of finding a cure

To find out more

Visit us on the web at www.cndr.org
Call us at 1-877-401-4494 (Canada & USA)
Email us at admin@cndr.org

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: Jan. 10, Feb. 14, Mar. 14, Apr. 11, May. 9, Jun. 13
Time: 1 p.m. - 3 p.m.
Place: Bridgeland Riverside Community Association
917 Centre Avenue NE
Contact: 403-620-1358 | Leslie@alsab.ca

ALS Family & Spousal Support Group

Dates: Jan. 28, Feb. 25, Mar. 25, Apr. 29
Time: 1 p.m. - 3 p.m.
Place: Quarry Park Library
Contact: 403-815-1567 | Rob@alsab.ca

Staying in Touch

Dates: Feb. 4, Apr. 1, Jun. 3
Time: 1 p.m. - 3 p.m.
Place: ALS Society Provincial Office
Contact: 403-620-1358 | Rob@alsab.ca

PLS & Kennedy's Group

Dates: Jan. 28, Feb. 25, Mar. 25, Apr. 29
Time: 1 p.m. - 3 p.m.
Place: Renaissance Condo Complex at North Hill Mall
1718 14 Ave NW
Contact: 403-620-1358 | Leslie@alsab.ca

Edmonton

ALS Support Group

Dates: Dec. 18, Jan. 15, Feb. 19, Mar. 19, Apr. 16
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: Dec. 18, Jan. 15, Feb. 19, Mar. 19
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: Dec. 21, Jan. 18, Feb. 15, Mar. 15, Apr. 19
Time: 2 p.m. - 3:30 p.m.
Place: ALS Society Edmonton Office
Contact: 780-487-0754 | SocietyNorth@alsab.ca

Staying in Touch

Dates: Jan. 18, Mar. 15, May. 17
Time: 11:30 a.m. - 1 p.m.
Place: ALS Society Edmonton Office
Contact: 780-487-0754 | SocietyNorth@alsab.ca

St. Albert

ALS & PLS Support Group

Dates: Dec. 7, Jan. 4, Feb. 1, Mar. 1
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: Jan. 25, Feb. 22, Mar. 29, Apr. 26
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: Jan. 26, Feb. 23, Mar. 30, Apr. 27
Time: 1 - 3 p.m.
Place: MS Society Office | 105, 4807 50 Avenue
Contact: 403-815-1567 | Rob@alsab.ca



There are many different ways that you and your family can support the ALS Society of Alberta this holiday season. Your support and donations help to make each day the best possible day for people living with and affected by ALS in Alberta, and make a direct impact within the community.

1

Become a monthly donor

You determine the amount of your monthly gift that will make a significant difference within the ALS community. You can adjust your pledge at any time, and each year you will receive an annual giving statement that you can use for your income tax.

2

Make a donation in honour or in memory of an individual

You can support a loved one by making a donation in their memory or in their honour. The family will receive a card informing them of your donation, which makes for a thoughtful and impactful holiday gift for a family who is affected by ALS.

3

Host a community event

The holidays are a great time to gather with your friends and family and do some fundraising. Whether its a gingerbread house competition, silent auction, or a night of fun at the bowling alley, there are many ways to incorporate ALS fundraising. If you have an idea for an event, contact Sonya@alsab.ca.

4

Planned giving

As part of your long-term financial planning, a planned gift can offer substantial tax and estate planning benefits and allow you to make a larger and longer-lasting gift to the ALS Society of Alberta. Donations can be made through a bequest in your will, gifts of securities, registered assets (RRSP and RRIF) and gifts of life insurance. Contact the Society for more information at info@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 _____ CVW# (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.